Centre for International Health

Desire to have children among people living with HIV in post-conflict Northern Uganda: A mixed methods study

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Doctor of Philosophy
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DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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“In this society we don’t ‘intend’ to have children, we just ‘have’ them”

Perplexed interviewer explaining why he found it difficult to ask the question about intent to have children among the participants

February 2009

"Barbara, it seems to me that your participants are facing incredible, competing social pressures: in their society, if they don't have children they are deemed, to a large degree, worthless. But if they do have children when they're HIV positive, they are viewed as irresponsible."

Sarah Prout (friend and colleague)

September 2011

ABSTRACT

Millions of people continue to contract the HIV virus every year, including thousands of children in Sub-Saharan Africa who mainly contract HIV through mother-to-child transmission (MTCT). Several factors are responsible for this continued transmission and include lack of access to HIV testing for at-risk populations and limited treatment services for people living with HIV (PLHIV). In addition, many HIV-infected children are born to PLHIV who desire to have children despite the risk of HIV transmission to their infants.

Informed by a pragmatic paradigm and using the Social Ecological Framework, this study explored the factors that influence desire to have children among PLHIV in Northern Uganda, a post-conflict region of high HIV prevalence. A mixed-methods design constituting a survey and semi-structured interviews was selected for this study. Between February and May 2009, 476 PLHIV from three HIV clinics within Gulu District were recruited to take part in the study. A 121-item questionnaire was administered to each respondent to collect socio-demographic information, sexual and reproductive history, family planning knowledge and use, fertility desires and intentions, and experiences of stigma. In the qualitative arm of the study, interviewers explored with 26 participants using a semi-structured guide their desire to have children, experiences of family planning and stigma in order to gain a deeper understanding of the desire to have children among PLHIV, the use of family planning methods and detailed understanding of the processes of stigmatisation of PLHIV in Northern Uganda.

This study found a high level of desire to have more children among PLHIV in Gulu District. Forty three percent of the respondents desired more children, including 54.2% of male respondents and 31.7% of female respondents ($p<.001$). Male sex, being single, and spouses' desire to have children were associated with an increased desire to have children. The factors influencing PLHIV's desire to have children included availability of highly active antiretroviral therapy (HAART), and prevention of mother-to-child transmission (PMTCT) programs, spouse, family and society expectations, the desire to have heirs, and cultural influences. Most of the

PLHIV were concerned about MTCT, some had personal health concerns and others were concerned about their children's futures.

This study also found a high level of knowledge of family planning methods (96%), but very low use of contraception at 38%. A significantly higher proportion of males (52%) than females (25%) were using contraception. Factors associated with the use of contraception were having ever gone to school, discussion of family planning with a health worker or with one's spouse, not attending the Catholic-based clinic and spouses' non-desire for children. The qualitative data revealed six major factors influencing contraception use, including personal and structural barriers to contraceptive use, perceptions of family planning, and decision-making, covert use of family planning methods and targeting of women for family planning services.

This study found that several factors were associated with the stigmatisation of PLHIV in Northern Uganda including being female, being on HAART, being older and having a diagnosis of HIV for longer. Using the Conceptual Framework of HIV/AIDS Stigma, this study further delineated the process of stigmatisation which included the factors that trigger stigma, stigma behaviours, outcomes of the stigmatisation process and the agents involved in stigmatisation of PLHIV. The latter included family, communities and the health system all of which can mitigate and/or enhance stigmatisation of PLHIV and lead to increased or decreased desire to have children among PLHIV.

In conclusion, the high level of desire to have children among PLHIV is understandable given the multi-level and multi-factor influences including factors at the individual level (sex, marital status, personal health concerns, concerns about the children's future and their potential infection, the desire to have heirs and fulfil family and societal obligations), interpersonal level (gender roles, interactions with spouses, family members and health workers), community level (community stigma and cultural norms) and structural levels (availability of HAART and PMTCT programs). Other superstructural factors influencing the desire to have children include the high levels of poverty, and gender inequality. Health workers and program managers at a local, national and international level must work with PLHIV for better health outcomes with provision of counselling, family planning services

and extension of HAART and PMTCT programs to both help reduce the incidence of HIV among children and meet the reproductive desires of PLHIV.

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DEDICATION

To Paul Ayella Watmon, my darling son, thank you for waiting

and

To my mother, thank you for being the wind beneath my wings

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LIST OF ABBREVIATIONS

3TC	Lamivudine
ABC	Abstinence, Being Faithful and Condom use
ACP	AIDS Control Program
AIC	AIDS Information Centre
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
AOR	Adjusted Odds Ratio
ART	Antiretroviral Therapy/Treatment
ARV	Antiretroviral drugs
AZT	Zidovudine
CBO	Community Based Organisation
CBT	Cognitive Behavioural Therapy
CD4	Cluster of Differentiation 4
CI	Confidence Interval
CIA	Central Intelligence Agency
CSW(s)	Commercial Sex Worker(s)
d4T	Stavudine
ddC	Zalcitabine
DDI	Didanosine
d.f.	degrees of freedom
EWD	Emotional Writing Disclosure
FHI	Family Health International
FP	Family Planning

FTC	Emtricitabine
GDP	Gross Domestic Product
GFATM	Global Fund for AIDS, Tuberculosis and Malaria
GNRH	Gulu National Referral Hospital
GoU	Government of Uganda
HAART	Highly Active Antiretroviral Therapy
HBC	Home Based Care
HC	Health Centre
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HLA	Human Leukocyte Antigen
HPV	Human Papilloma Virus
HSV-2	Herpes Simplex Virus, Type 2
IDP	Internally Displaced Person/People
IDU	Injecting Drug User
IEC	Information, Education and Communication
IMR	Infant Mortality Rate
IPPF	International Planned Parenthood Federation
IQR	Interquartile Range
JCRC	Joint Clinical Research Centre
KYE	Know Your Epidemic
KYR	Know Your Response
LGV	Lymphogranuloma Venereum
LRA	Lord's Resistance Army

MARP	Most At Risk Populations
MOH	Ministry of Health
MoT	Modes of Transmission
MRC	Medical Research Council
MSIU	Marie Stopes International Uganda
MSM	Men who have sex with men
MTCT	Mother-to-child transmission
NGO	Non-Governmental Organisation
NNRTIs	Nonnucleoside Reverse Transcriptase Inhibitors
NRTIs	Nucleoside Reverse Transcriptase Inhibitors
NSP	National Strategic Plan
OCHA	Office for the Coordination of Humanitarian Affairs
OR	Odds Ratio
OVC	Orphans and Vulnerable Children
PEPFAR	President's Emergency Plan for AIDS Relief
PI	Protease Inhibitors
PLHIV	People Living With HIV
PMTCT	Prevention of Mother-to-Child Transmission
PYAR	Person Years At Risk
RCT	Randomised Control Trial
RHSP	Rakai Health Services Program
RHU	Reproductive Health Uganda
RNA	Ribonucleic Acid
s.d.	Standard Deviation

SPSS	Statistical Package for the Social Sciences
SRH	Sexual and Reproductive Health
STI(s)	Sexually Transmitted Infection(s)
TASO	The AIDS Support Organisation
TB	Tuberculosis
UAC	Uganda AIDS Commission
UBOS	Uganda Bureau of Statistics
UDHS	Uganda Demographic and Health Survey
UFM	Under Five years Mortality rate
UHSBS	Uganda HIV/AIDS Sero-Behavioural Survey
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UPDF	Uganda People’s Defence Force
USD	United States Dollar
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

DEFINITIONS

Antiretroviral drugs: drugs used to treat infections caused by retroviruses. Though generally used to refer to all drugs that can be used in various combinations to prevent mother-to-child transmission of HIV and for pre- and post-exposure prophylaxis, in this thesis, the term is used to refer to "highly active antiretroviral therapy", HAART. The term is also used interchangeably with antiretroviral therapy (ART).

Casual sex: sex with a non-regular partner.

Clients of sex workers: someone, male or female, who pays for sex.

Cohabiting: living together in a sexual relationship, though may not be formally married. For this study, cohabitation is considered a stable, long-term relationship.

Commercial sex worker: someone, male or female, who exchanges sex for money.

Commercial sex: the dependency on sex for money or other items as an occupation.

Cross-generational sex: sex with a much older person, particularly when there is an age difference of ten years or more between the sexual partners.

Drivers of the HIV epidemic: individual, social and structural factors that increase an individual's or population's vulnerability to the acquisition of HIV infection. The term 'driver' relates to the structural and social factors, such as poverty, gender inequality and human rights violations, that are not easily measured but which increase people's vulnerability to HIV infection (UNAIDS, 2007b).

Fertility desire among PLHIV: in this study is defined as "the wish or intention to have more children despite the diagnosis of HIV".

Health Centre II: out-patient clinics treating common diseases and offering antenatal care. This health facility is headed by an enrolled nurse who works with a midwife, two nursing assistants and a health assistant. According to the Ugandan government's health policy, every parish is supposed to have a Health Centre II (Uganda Bureau of Statistics, 2011).

Health Centre III: health centres with facilities that include an operation room and a section for minor surgery headed by a clinical officer. Every county in Uganda should have this facility which offers continuous basic preventive and curative care together with support supervision of the community and the Health Centre II facilities under its jurisdiction (Uganda Bureau of Statistics, 2011).

Health Centre IV: a mini hospital that provides the kind of services found at Health Centre III with additional wards for men, women, and children and ability to admit patients. It should have a senior medical officer and another doctor as well as a theatre for carrying out emergency operations. It serves a county or a parliamentary constituency (Uganda Bureau of Statistics, 2011).

Highly active antiretroviral therapy (HAART): the combination of antiretroviral drugs used to treat people living with HIV. Taken in combination, the drugs markedly reduce the viral loads of HIV-infected people, and lead to improvement in immunity and overall health. In this thesis, HAART is occasionally referred to as antiretroviral therapy (ART) or antiretroviral drugs (ARV(s).

HIV Positive/Infected: infected with the HIV virus but may or may not have AIDS.

Incidence: number of new infections per number in the population at risk in a specific period in time.

Prevalence: total number of cases with an infection in a population at a point or period in time.

Most-at-risk-populations: populations in which there is a concentration of risk for HIV transmission. This depends on the populations and the region but may include

injecting drug users, commercial sex workers and their clients, and men who have sex with men. These populations may drive the majority of new infections in the general population.

Multi-sectoral: a strategy which involves all sectors (health, education, agriculture, justice etc) in a holistic approach to the HIV epidemic.

Mutually monogamous sex: sex that occurs with only one partner.

National Referral Hospitals: facilities which provide preventive, outpatient, maternity, inpatient health services, emergency surgery, blood transfusion, laboratory and other general services. They also provide in-service training, consultation and research in support of community-based health care programs. In addition, they provide comprehensive specialist services and are involved in teaching and health research (Uganda Bureau of Statistics, 2011).

Occupation: the nature of task and duties performed during the reference period preceding the interview by persons in paid employment, unpaid family work or self-employment jobs (Uganda Bureau of Statistics, 2011).

Risk: probability that an event will occur e.g. someone will acquire an infection, die or become ill within a certain period.

Risk factor: "an aspect of personal behaviour or life-style, an environmental exposure, or an inborn or inherited characteristic, that, on the basis of epidemiologic evidence, is known to be associated with health-related condition(s) considered important to prevent" (Last, 2001). In the HIV context, these may include injecting drug use with contaminated needles and syringes, unprotected sex with an HIV-infected person, and multiple concurrent sexual partners with low and inconsistent condom use.

Sexual abstinence: avoidance of all sexual intercourse, genital contact or genital stimulation.

Spouse/partner: in this thesis, a 'spouse' is a person with whom the respondent is either formally married or cohabiting; while 'partner' may include a sexual partner with whom the respondent may or may not be living.

Transactional sex: sex in exchange for money or other gifts. Usually the person offering sex is not regarded as a sex worker, but there may be an element of exploitation especially when there is age, economic and social disparity.

Unprotected sex: heterosexual or homosexual, penetrative (vaginal or anal) sex without use of a condom.

Vulnerability: a state whereby individuals or communities are not able to protect themselves against the spread of HIV. This may be caused by personal factors e.g. lack of knowledge or skills, or structural factors that prevent access to quality services for prevention and cure. Other relevant factors may include societal or cultural norms and beliefs that determine, and particularly impede, access to care and services or change in health behaviour

CHAPTER 1: INTRODUCTION AND OVERVIEW

1.0 Introduction to the Chapter

This chapter provides a general overview of the background and aims of the study. This is followed by an overview of the thesis, including the rationale for the layout of the thesis.

1.1 Background to the Study

The HIV epidemic is well into its third decade and millions of men, women and children continue to be infected with this deadly virus. Though HIV infection is no longer a death sentence in many developed countries, in countries in Sub-Saharan Africa where access to highly active antiretroviral therapy (HAART) is limited, many people living with HIV (PLHIV) will die of this disease without access to basic health services, let alone HAART. Fortunately, in some Sub-Saharan African countries, there has been an increase in the number of people accessing HAART and programs to prevent mother-to-child transmission (PMTCT), so the number of people dying from Acquired Immune Deficiency Syndrome (AIDS) has reduced drastically.

Before the availability of HAART, there was limited research interest around the desire to have children among PLHIV. Now that the life expectancies of PLHIV have improved with the availability of this life-prolonging therapy, there is an increasing interest in the reproductive behaviour of PLHIV and how best to prevent secondary transmission of HIV infection to sexual partners and infants. In particular, pregnancy and the desire to have children among PLHIV have been problematised because of the risk of HIV transmission from mother to child. In fact, one of the most contentious issues facing public health is the need to reduce further transmission of HIV from mother to child versus the desire of PLHIV to have more children. In general, policies have discouraged PLHIV from having any children (Mantell, Smit, & Stein, 2009).

This thesis examines the desire to have children among PLHIV living in Northern Uganda in order to provide some insight into the context within which many PLHIV

continue to desire to have children despite the risk of transmission of HIV to their infants. Northern Uganda is a post-conflict region which has a high HIV prevalence estimated at 8.2% (9% for women and 7.1% for men) (Ministry of Health Uganda & ORC Macro, 2006), in contrast to the national average of 6.4%. This study was timely because the region is far behind the rest of the country in social, health and economic indicators and is in dire need of culturally-appropriate and evidence-based programs that support PLHIV and other people at risk in the region. This thesis sets out to provide a holistic description of the fertility desires of PLHIV in Northern Uganda so that counselling, care and treatment programs can be designed to meet the reproductive needs of PLHIV without sacrificing their health, or that of their partners or newborns.

1.2 Fertility desires and intentions among people living with HIV

There is a significant body of literature that has documented the factors associated with the desire and intent to have children among PLHIV. For the purpose of this thesis, fertility desire among PLHIV is defined as the "wish or intent to have more children despite the diagnosis of HIV". Therefore this study did not explore the desire to have children among people who are unknowingly infected with HIV. Early on in the HIV epidemic, pregnancies and desire to have children among PLHIV were problematised because policy-makers were particularly concerned about the implications of HIV transmission (Cooper, Harries, Myer, Orner, & Bracken, 2007). This was understandable during the 1980s and 1990s, where in countries with significant numbers of HIV-infected people, mother-to-child (vertical) transmission of HIV infection and unprotected sexual activity were major risk factors for transmission of HIV, and re-infection with different strains of HIV (Thorton, Romanelli, & Collins, 2004). HAART and PMTCT programs were not widely available at that time and policies in some countries generally discouraged HIV-infected individuals from having children as a measure to reduce the number of children born with HIV (Cooper, et al., 2007). The desire of HIV-infected persons to have children has significant implications for the transmission of HIV to sexual partners and newborns (Chen, Phillips, Kanouse, Collins, & Miu, 2001), particularly in developing countries where access to PMTCT and HAART interventions is not universal.

Previous studies investigating fertility desires among HIV-infected men and women revealed that a significant proportion of HIV-affected couples desire to have children despite their HIV status (Adair, 2007; Chen, et al., 2001; Richter, Sowell, & Pluto, 2002; Santos, Ventura-Filipe, & Paiva, 1998; Wesley et al., 2000). More than a quarter of a nationally representative sample of PLHIV in the US desired to have more children, with over 50% of both women and men expecting to have at least one more child in the future (Chen, et al., 2001). In a study of HIV-positive and negative African-American women in New Jersey, USA, desire for children did not vary by HIV serostatus (Wesley, 2003) while in Nigeria, 71.4% of PLHIV continued to desire to have children (Chama, Morrupa, & Gashau, 2007). A Canadian study of HIV-positive women also reported that 69% of the respondents desired to give birth with 57% of them intending to have children in the future (Loutfy et al., 2009).

There is also evidence that a substantial proportion of HIV-infected individuals have continued to have children. This was true in both resource-limited countries (Bunnell et al., 2006; Olley, Seedat, Gxamza, Reuter, & Stein, 2005; Santos, et al., 1998) as well as in Europe and North America (Chen, et al., 2001; Craft, Delaney, Bautista, & Serovich, 2007; Loutfy, et al., 2009; Smits et al., 1999). In the United States, one study found that a third of a HIV-infected group of women in Ohio State had become pregnant since receiving their diagnosis (Craft, et al., 2007), while 55% of PLHIV in Louisiana (Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005) and 40% of PLHIV from the Southern USA states of Georgia, North Carolina and South Carolina (Sowell, Murdaugh, Addy, Moneyham, & Tavokoli, 2002) had been pregnant since their HIV diagnosis. In Brazil, 15% of HIV-infected women had at least one child post diagnosis (Nóbrega et al., 2007). In a cohort study of 306 HIV-positive women in Burkina Faso, the incidence of pregnancy was similar to the general population, despite the women having received counselling against pregnancy and the provision of family planning services (Nebié et al., 2001).

In contrast, other studies have found that HIV-infected women who are aware of their status are less likely to want, and to have, a child. Studies that have compared HIV-infected and HIV-negative people have found that there is a marked reduction in the desire to have children among HIV-infected people. A longitudinal study in

Malawi that compared the desire to have children between HIV-negative and HIV-infected female participants found that over 12 months, the desire to have children in the former group remained an estimated three times higher than in the latter (Taulo et al., 2009). The desire to have children also decreased over time among the HIV-infected women in that study. In South Africa, pregnancy desire was significantly lower in HIV-infected than HIV-negative women (Peltzer, Chao, & Dana, 2008).

Similarly, in a cross sectional study of 1,803 PMTCT attendees in Kenya, researchers found that HIV-infected women were almost eight times less likely to want to have children than HIV-negative women (Baek & Rutenberg, 2005). This study reported that these women were concerned about their own health, and worried that more pregnancies would make them deteriorate faster. They also felt that they should take care of their existing children and were worried about transmission of HIV to future children (Baek & Rutenberg, 2005). Seventy percent of PLHIV in Georgia and South Carolina, USA, had no plans to have any more children (Richter, et al., 2002), while 89% of PLHIV female respondents in Zimbabwe felt that PLHIV couples should not have children (Feldman & Maposhere, 2003). A New Orleans study showed that HIV-infected women continued to have children but were less likely to do so than women of the same age in the general population (Bedimo, Bessinger, & Kissinger, 1998).

Several studies conducted in Uganda have reported that generally, there is a low level of desire to have children among PLHIV. Table 1 summarises the studies conducted in Uganda, in particular highlighting the fertility desires of PLHIV from Western and Eastern Uganda. This table also summarises information on the use of family planning in these studied populations which will be discussed in Chapter 7. In regards to fertility desires among PLHIV in Uganda, Heys et al. (2009) found in a study in Kabarole, Western Uganda that the desire to stop childbearing was 6.25 times greater among HIV-infected men and women compared to HIV-negative participants ($p<.001$), with 79% of PLHIV who wanted to stop having children saying the desire to stop was directly related to their HIV-infected status. In this study, only 14% of HIV-infected participants wanted to have more children.

Other studies in Uganda have found similarly low percentages with less than 7% of female PLHIV participants in Tororo and Busia, Eastern Uganda (Homsy et al., 2009), 18% of PLHIV participants (male and female) in Jinja, Eastern Uganda (Nakayiwa et al., 2006), and 14.6% of female PLHIV participants in Mbarara, South Western Uganda (Maier et al., 2009) wanting to have more children. In a more recent study conducted in several HIV clinics across Northern, Western and Central Uganda, only 24% of male respondents and 19% of female respondents said they wanted more children (Wanyenze et al., 2011). As explained in Chapter 3, there are a range of factors associated with the desire to have children among PLHIV but as discussed in Chapter 7, not all PLHIV who do not desire to have children are able to access the family planning services they need.

Despite the significant amount of literature that has documented the desires to have children among PLHIV, none of the studies have extensively examined the multi-level and multi-factor influences on this desire. Furthermore, none of these studies had been conducted in a conflict/post-conflict region. Accordingly, the overall purpose of this study was to gain a better understanding of the fertility desires and intentions of HIV-infected men and women living in post-conflict Northern Uganda. Particularly, this study aimed to explore the determinants of fertility desires of HIV-infected women and men attending three HIV clinics in Gulu district, Northern Uganda, the structural/environmental, community and individual factors that enhanced or restricted their ability to plan, space and limit their family sizes, and investigate the level of integration of family planning services with HIV programs at health facility, district and national levels. The next Chapter describes the factors that influence the desire to have children among PLHIV in Uganda and other countries, but first the layout of this thesis is described below.

Table 1: Fertility desires and family planning use among PLHIV in Uganda

Author/ Year	Location	Participants/Design	Fertility desire	Family planning
Andia 2009	Mbarara Nov 2005-Jun 2006	484 HIV-infected Females Cross sectional	14% want more children Not wanting more children was associated with: • use of contraception AOR=2.80, 95% CI: 1.23-6.38 and • use of barrier methods AOR=2.66, 95% CI: 1.27-5.59	85% of sexually active using FP 84% using barrier methods 30% using hormonal High level of dual use Women using HAART twice as likely to use contraception AOR=2.64, 95% CI: 1.07-6.49 and thrice as likely to be using barrier methods AOR=3.62, 95% CI: 1.54-8.55
Heys 2009	Kabarole 2006	199 HIV-infected 222 HIV-negative Cross sectional Mixed methods	14% HIV-infected wanted more children 53% HIV-negative wanted more children HIV-infected 6.25 times more likely to want to stop child bearing than HIV-negative	74% of HIV-infected using FP compared to 13% HIV-negative Most HIV-infected using condoms Unmet need for highly effective contraception was 90% among HIV-infected 3.5% HIV-infected using dual methods
Homsy 2009	Tororo and Busia May 2003-	711 HIV-infected Females Prospective cohort	Under 7% wanted more children 26% of their partners wanted more children Of those 176 sexually active who did not	63% of sexually active using condoms 14% using hormonal contraception 4.3% using dual contraception

Author/ Year	Location	Participants/Design	Fertility desire	Family planning
	June 2006		want children: • 33% did not use a method • 53% used condoms • 86% did not use hormonal or permanent • 96% did not use dual methods	
Maier 2009	Mbarara Nov 2005-June 2006	501 HIV-infected Females Cross sectional	14.6% desired to have children HAART associated with increased desire to have children AOR = 2.99 , 95% CI: 1.38-6.28 Decreased odds of desire associated with: • Increased age AOR = 0.33, 95% CI: 0.19-0.56) • Having WHO stage 3-4 AOR= 0.46, 95% CI: 0.22-0.95 • Widowed AOR =0.24 , 95% CI: 0.08-0.75 • Increased number of live births AOR = 0.35 , 95% CI: 0.16-0.74	27% sexually active recent contraceptive use 60.6% always use reliable methods 25% using condoms (of these, 56.2% always used condoms)

Author/ Year	Location	Participants/Design	Fertility desire	Family planning
Nakayiwa 2006	Jinja Oct 2003-June 2004	488 Male 604 female HIV-infected	18% of sexually active PLHIV desired more children 16% of total desired to have children 27% males and 7% of females desired more Fertility desire significantly associated with: • younger age AOR=0.32, 95% CI: 0.16 – 0.65 • female AOR=0.12, 95% CI: 0.08-0.20 • number of living children AOR=0.82, 95% CI: 0.75-0.90 • belief that HIV infected women should have children AOR=0.23, 95% CI: 0.16-0.36 Fertility desire not associated with • PMTCT knowledge OR=1.14, 95% CI: 0.78 – 1.68 • Experience of death of a child OR=0.82, 95% CI: 0.58 – 1.16	

Author/ Year	Location	Participants/Design	Fertility desire	Family planning
Wanyenze 2011	12 clinics, 3 districts (Gulu, Kabarole, Kampala) July-Oct 2009	441Male 659 Female All HIV-infected Cross Sectional	21% desired more children 24.4% males desired more compared to 19% females: p = .04	58% using FP 31% had been pregnant since HIV diagnosis 43% of pregnancies that occurred after HIV diagnosis were unplanned 216 female pregnancies: 80 unplanned. 123 male pregnancies: 25 unplanned. Among females who did not desire to have children: 70% were using FP. Among married/cohabiting and not pregnant females, 80% using FP. Those who did not discuss number of children and non-disclosure of HIV status less likely to be using contraception AOR= 0.40, 95% CI: 0.02-0.81 and AOR= 0.30, 95% CI: 0.10-0.85

AOR, adjusted odds ratio; CI, confidence interval; FP, family planning; HAART, highly active antiretroviral therapy; OR, odds ratio; PLHIV, people living with HIV; PMTCT, prevention of mother-to-child transmission; WHO, World Health Organization

1.3 Overview of the Thesis

This thesis is a 'hybrid' thesis which is a combination of the traditional typescript thesis, published papers and a paper submitted for publication. The current chapter has provided the background of the study, together with a summary of the literature around fertility desires and intentions among PLHIV. Chapter 2 presents the current global HIV epidemic as well as the HIV epidemics in Sub-Saharan Africa, Uganda and Northern Uganda. The purpose of the chapter is to explicate the context of HIV transmission in Sub-Saharan Africa, the vulnerability of women, girls and children, the drivers of the epidemic, and prevention and control efforts in Uganda. Most of these contextual factors also exist in Northern Uganda and the detailed analysis of these factors gives an important context to the HIV epidemic in Gulu District, Northern Uganda.

Chapter 3 presents a review of the literature around factors associated with the desire to have children among PLHIV. Chapter 3 also contains a published peer-reviewed systematic review of the literature around the desire to have children among PLHIV. Chapter 4 explains the study's research methodology, design and rationale. It details the research aims and objectives, the research paradigm and the conceptual framework used in this thesis, and describes the study site, and the use of both qualitative and quantitative methods.

The findings of the study are presented in Chapters 5, 6 and 7. Specifically, Chapter 5 summarises the respondents' sociodemographic characteristics, reproductive history, fertility preferences, HIV knowledge and HIV history. The chapter also contains the quantitative and qualitative findings on the desire to have children among PLHIV in Gulu, Northern Uganda. Presented separately in Chapter 6 are the quantitative and qualitative findings on stigma and its relationship with the desire to have children. A detailed discussion on stigma definitions, conceptual frameworks, types of stigma, outcomes of stigma and discrimination of PLHIV, and experiences of HIV-related stigma in Sub-Saharan Africa, Uganda and Northern Uganda, provides a context to understanding the stigma experiences among PLHIV in Gulu

District. Chapter 7 presents the quantitative and qualitative findings on family planning use among PLHIV.

The last chapter, Chapter 8, contains an overview of the research design and process, with an emphasis on the complementarity of the qualitative and quantitative methods, a summary of the major findings, the recommendations of the study and the final concluding statement of the thesis. The appendices 1-9 contain the phases of the study, matrix of objectives and methodology, and a map of Uganda showing Northern Uganda. They also include the questionnaires (English and Luo versions of the male and female questionnaires), the semi-structured interview guide, the information sheets and consent forms and the copyright permissions to reproduce the peer-reviewed articles in this thesis. The bibliography contains all the references in the thesis, including the references in the published papers.

In regards to the style of writing, in this thesis both the first person (subjective) and third person (objective) voice are used. The objective voice is used for the quantitative arm of the study and the subjective voice for the qualitative arm of the study. The interviewees in the quantitative arm of the study are referred to as 'respondents' while the interviewees in the qualitative arm of the study are referred to as 'participants'. Occasionally, the pronoun 'we' is used, especially when writing about the qualitative data collection because the data collection process was a collaborative process between the participants, interviewers and the researcher.

CHAPTER 2: THE GLOBAL HIV EPIDEMIC AND THE HIV EPIDEMICS IN SUB-SAHARAN AFRICA, UGANDA AND NORTHERN UGANDA

2.0 Introduction to the Chapter

This chapter commences with an overview of the global dimensions of the HIV epidemic. This is followed by a discussion of the HIV epidemics in Sub-Saharan Africa and Uganda in order to provide context for the HIV epidemic in Northern Uganda. The risk factors, the drivers of the epidemics, and the trends in prevalence and incidence globally, in Uganda and in Northern Uganda are also discussed in this chapter.

2.1 The Global HIV Epidemic

Present Global HIV situation

In 2009, between 31.4 million and 35.3 million people were estimated to be infected with HIV globally: of these, about 30.8 million were adults, 15.9 million were women and 2.5 million were children (UNAIDS, 2010). The global adult prevalence rate for 2009 was 0.8%. Though the incidence of HIV had declined since the 1990s, new HIV cases in 2009 were still estimated to be between 2.3 million and 2.8 million; of these, about 2.2 million were adults and 370,000 were children. The number of new infections in 2009 was 26% lower than the number of new infections in 1996, when was it estimated to be 3.5 million. In 2009, there were an estimated 1.8 million deaths due to AIDS-related illnesses (UNAIDS, 2010). Of note is that the number of PLHIV has been increasing as a result of the incident cases of HIV, as well as the effect of HAART on prolonging the lives of PLHIV (UNAIDS, 2009).

Types of HIV epidemics

UNAIDS (2007b) classified HIV epidemics into three categories namely, low grade epidemics, concentrated epidemics, and generalised epidemics. In a low-grade epidemic, HIV infection is confined to high risk groups such as injecting drug users (IDUs) and the prevalence has not exceeded 5% in any sub-population. Such epidemics are usually new epidemics where the transmission networks are diffuse,

that is, there is a low level of sexual partner exchange. In this scenario, UNAIDS (2007b) advocates that information about the at-risk populations be collated in order to understand among which populations the HIV epidemic is spreading and why it is not spreading to other populations. Studies of sexual networks and the risk behaviours of these populations are essential for preventing the HIV infection spreading into the general population.

In a concentrated epidemic, HIV has spread rapidly in a defined sub-population, but is not yet well established in the general population. The HIV prevalence exceeds 5% in at least one sub-population, but is less than 1% in pregnant women. These sub-populations usually include men who have sex with men (MSM), IDUs or commercial sex workers (CSWs) and their clients. The size of the at-risk populations as well as the interactions with the general population will determine the future of the epidemic (UNAIDS, 2007b). In countries such as Thailand, IDUs and CSWs are usually the bridging population to the general population. In this scenario, it is essential that the epidemic is prevented from becoming a generalised epidemic.

In a generalised epidemic, HIV is firmly established in the general population and the HIV prevalence is consistently over 1% in pregnant women attending antenatal clinics (UNAIDS, 2007b). All sexually active people are at high risk of contracting the virus in a generalised epidemic, whether they have multiple partners or not. In this situation, HIV sero-discordance and multiple sexual partnerships lead to a large proportion of new infections (UNAIDS, 2007b) and people who are usually considered to be at low risk, for example people with one sexual partner, are also at high risk of contracting HIV infection. Expanded access to HIV prevention and support programs is essential in this scenario, as well as education of the general population. Monitoring of the generalised epidemic is essential through surveillance of the general population as well as surveillance of other high-risk groups such as MSM and IDUs.

For programmatic purposes an additional categorisation, hyperendemic epidemic, is also used. This is a situation where the severity of the HIV epidemic requires a substantial allocation of resources for control of the epidemic (UNAIDS, 2007b). In a hyperendemic epidemic, the HIV prevalence exceeds 15% in the adult population.

This type of epidemic is usually driven by extensive heterosexual, multiple concurrent partner relationships with low and inconsistent condom use but also driven by other social, cultural, economic and structural factors. In this scenario, very high numbers of people are at risk of contracting HIV and concerted efforts must be made to control further spread of the infection. This is the current situation in Southern Africa, where the highest number of PLHIV can be found and in countries such as Botswana, Swaziland, South Africa and Zimbabwe, where HIV prevalence is very high (UNAIDS, 2007b). In 2009, HIV prevalence among adults aged between 15 and 49 years in Botswana, Swaziland, Lesotho, South Africa and Zimbabwe was estimated at 24.8%, 25.9%, 23.6%, 17.8% and 14.3%, respectively (UNAIDS, 2010), some of the highest HIV prevalences in the world.

However, Wilson (2006) cautioned that broad classification of HIV epidemics into 'concentrated' or 'generalised' can be deceptive and also lead to inappropriate allocation of resources. Wilson argued that the definition of generalised and concentrated epidemics needs to be adjusted to take into account HIV transmission dynamics, particularly the factors that drive the epidemic. He consequently redefined a concentrated epidemic as one where HIV transmission is mainly driven by particular populations and if interventions among these groups would protect the wider population from further transmission. Furthermore an HIV epidemic is generalised if HIV transmission is already occurring among the general population and interventions in key vulnerable groups will not in themselves protect the general population from further transmission (Wilson, 2006). Therefore Wilson reclassified the HIV epidemics of Ghana, Kenya and Zambia. In Ghana, the HIV prevalence in the general population is 2%, the HIV prevalence among CSWs is 80%, and 76% of new HIV infections among adult males of aged 15-49 is attributable to contacts with CSWs. Accordingly, this is a concentrated HIV epidemic and interventions among CSWs are a major priority in order to protect the general population (Wilson, 2006).

In Kenya, the HIV prevalence in the general population is estimated at 10%, HIV prevalence among sex workers is 60%, and approximately 50% of infections can be attributed to sex work (Wilson, 2006). Kenya thus has a mixed epidemic, with HIV infections arising from both high-risk vulnerable groups and the general population; interventions in both groups are necessary to control the epidemic. In Zambia, the

adult HIV prevalence is approximately 15% and the HIV prevalence is 50% among sex workers. Less than 5% of HIV infection may be attributed to sex workers, their clients and other populations, such as soldiers and truck drivers. Thus Zambia has a highly generalised epidemic in which most transmission is driven mainly by sexual behaviour in the general population. In this situation, large-scale, fundamental changes in community norms, sexual values and practices, together with social and community change processes, are critical (Wilson, 2006).

UNAIDS (2007b) emphasised that HIV epidemics do not necessarily remain static but can continue to evolve: low level epidemics can quickly become concentrated, or mixed epidemics can evolve into generalised or hyperendemic epidemics, or the epidemic may decline like what happened in Uganda in the 1990s, or remain stable. Thus the spread of the HIV epidemic is not uniform, and the global epidemic continues to evolve. Proper description and evaluation of individual countries reveal that HIV epidemics are dynamic (Beyrer et al., 2010). HIV epidemics in Central Asia and Eastern Europe that were initially concentrated among IDUs are now more commonly spread via heterosexual routes (UNAIDS, 2009). Initial control of the epidemic in high-income countries has seen a resurgence of new infections among MSM (Sullivan et al., 2009; Vu et al., 2010). Between 1996 and 2000, there was a 5.3% per year decrease in notifications among MSM in Australia, UK, Germany, Netherlands and Canada, but this was followed by a 3.3% per year increase in HIV notifications between 2000 and 2005 (Sullivan, et al., 2009).

In high-income countries, there has also been an increase in heterosexually-acquired HIV. In the United Kingdom, for instance, many newly diagnosed PLHIV have had sexual partners from high-prevalence countries or were born in high-prevalence regions such as Sub-Saharan Africa (Health Protection Agency, 2009). In 2008, just over two thirds of the HIV infections acquired heterosexually in the UK were among people with African ancestry, and most of them acquired the infection abroad, particularly from Africa. Therefore the HIV pandemic remains one of the most serious challenges to global public health, in particular because of the need to tailor HIV prevention efforts to the community's requirements, as well as to continue to monitor the trends of the epidemic within each region. Prevention efforts within key high-risk populations remain a major element of individual national strategies to

control the spread of the epidemic (UNAIDS, 2009). Evolution of local and regional epidemics will depend on the local social, epidemiological, and cultural conditions as well as the national and local responses to control of the spread of the infection. It is therefore essential to have ongoing data collection and analysis to assess the epidemic dynamics and adjust appropriate HIV-prevention strategies and programs accordingly (UNAIDS, 2007b).

Transmission of HIV

HIV can be transmitted via various routes including transfusion of whole blood and blood products, sexual intercourse (oral, vaginal and anal), mother-to-child (vertical transmission) and through needle stick injuries and sharing of needles for injection drug use, though the risks of transmission vary according to the route. Globally, heterosexual transmission and MTCT of HIV remain the two major modes of transmission, with blood transfusion being the third most important (Piot & Bartos, 2002). Table 2 presents the relative risks of HIV transmission via several routes including blood transfusion, needle sharing, sexual intercourse and MTCT (Centers for Disease Control and Prevention, 2005; Coovadia, 2004; Piot & Bartos, 2002). Though the heterosexual route is fairly inefficient, transmission is enhanced by several factors including presence of sexually transmitted infections (STIs), higher viral loads, and lower CD4 counts and during receptive anal intercourse.

Mother-to-child transmission of HIV is an effective route of transmission and occurs intrauterine, intrapartum and postpartum (Ellington, King, & Kourtis, 2011; Kourtis, Lee, Abrams, Jamieson, & Bulterys, 2006). In countries with high levels of breastfeeding and in the absence of interventions such as PMTCT and HAART, transmission via MTCT is up to 35% (Piot & Bartos, 2002). In contrast, in developed countries MTCT has reduced to as low as 1-4% as a result of use of HAART, caesarean sections for HIV-infected mothers, and formula feeding for infants (Coovadia, 2004; Piot & Bartos, 2002). According to Kourtis et al. (2006), 50% of HIV infections caused by MTCT in non-breastfeeding populations, occurs towards the end of the intrapartum period and up to 40% of HIV MTCT infections in breastfeeding populations occurs postpartum.

Table 2: Estimated per-act risk for acquisition of HIV, by exposure route

Exposure route	Risk per 10,000 exposures to an infected source*
Blood transfusion	9,000
MTCT in developing countries	2500-3500
MTCT in developed countries (HAART, caesarean section and formula feeding)	100-400
Needle-sharing injection-drug use	67
Receptive anal intercourse	50
Percutaneous needle stick	30
Receptive penile-vaginal intercourse	10
Insertive anal intercourse	6.5
Insertive penile-vaginal intercourse	5
Receptive oral intercourse	1
Insertive oral intercourse	0.5

* Estimates of risk for transmission from sexual exposures without condoms;
HAART, highly active antiretroviral therapy; MTCT, mother-to-child transmission.
Sources: Piot & Bartos (2002), Coovaida (2004) and Centers for Disease Control and Prevention (2005)

Mother-to-child transmission, as explained above occurs prenatally, during labour and delivery and postnatally. However there are several host factors associated with increased or decreased MTCT of HIV. These include genetic factors in both mother and infant, such as foetal gender and HLA type and maternal-foetal HLA concordance (Ellington, et al., 2011). Maternal and infant co-infections that enhance MTCT include chorioamnionitis, ulcerative genital infections (Herpes Simplex Virus, Type 2 (HSV2) and syphilis), Hepatitis C, malaria, tuberculosis (TB), mastitis, breast abscesses and oral candidiasis in the infant. Chorioamnionitis is associated with preterm labour and premature rupture of membranes both of which are associated with increased MTCT, as they lead to the birth of low birth weight infants who are immunocompromised, and have immature skin and mucosal membranes (Ellington, et al., 2011). Syphilis and HSV2 are associated with increased genital

shedding of HIV, while malaria and active TB infection increase viral load and therefore MTCT. Other factors include maternal behavioural factors (illicit drug use, alcohol and tobacco use), infant feeding practices (breastfeeding, mixed feeding and premastication of food) and maternal nutrition status, particularly Vitamin A deficiency (Ellington, et al., 2011). Therefore in order to prevent/reduce MTCT of HIV, other interventions such as improvement in maternal nutrition status and control of infections should also be considered.

Although, MTCT of HIV has been extensively studied in chronically-infected women, maternal acquisition of HIV-1 during and after pregnancy and its impact on MTCT has been underestimated and overlooked (Lockman & Creek, 2009). Acute maternal infection during and after pregnancy has an impact on MTCT of HIV as high maternal HIV-1 viral loads, as during acute infection, is significantly associated with vertical transmission (Mock et al., 1999). Although HIV transmission can occur at any maternal plasma HIV-1 RNA level, transmission is more likely to occur at higher levels (Lockman & Creek, 2009). In a case study of 104 women in China who were postnatally infected with HIV via blood transfusions, transmission rate to their infants via breastfeeding was 35.8% (Liang et al., 2009). This was in marked contrast to lower rates found in other studies of chronically-infected women with lower postnatal transmission rates ranging from 9-16%. Therefore the risks and timing of HIV transmission during chronic and acute stages of infection of HIV varies. Hence it is necessary that there is ongoing identification of the risks of new maternal infection during and after pregnancy so that interventions to prevent MTCT such as repeat ANC testing, late antiretroviral therapy for mother and infant and replacement feeding can be instituted (Lockman & Creek, 2009).

Because these resources to prevent MTCT of HIV are not universally available in middle and lower income countries, WHO provides guidelines for management of mother and child depending on the resources available and the state of the mother's health (World Health Organization, 2010). Ideally both mother and infant should receive antiretroviral therapy (ART): if the HIV-infected mother needs treatment for herself, it is recommended that she is started on HAART. If she doesn't need therapy for her own health, it is still advised that she start on ART prophylaxis from 14 weeks of gestation through to one week after delivery. WHO recommends that HIV-

exposed infants should be given up to 4-6 weeks of prophylaxis if they are being breastfed. If possible, replacement feeding should be considered; but where it is not feasible, acceptable, safe or affordable, mothers are advised to exclusively breastfeed their infants for the first 6 months and rapidly wean them in order to reduce the transmission rates (Piot & Bartos, 2002).

Antiretroviral therapy

In the mid 1980s, zidovudine (AZT), the first antiretroviral drug, was used to prolong the lives of PLHIV with advanced disease (Amoroso, Davis, & Redfield, 2002). This was soon followed by the development of other antiretroviral agents and mono and dual therapy were used to improve the lives of PLHIV, mainly in developed countries. Unfortunately AZT monotherapy and later dual therapy quickly resulted in drug resistance, reducing the efficacy of therapy in many patients. To date there are a number of antiretroviral drugs available and used in combination, result in suppression of viral replication and improvements in immune function. These main classes of antiretroviral drugs include nucleoside and nucleotide reverse transcriptase inhibitors (NRTIs/NtRTIs), nonnucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PI), the latter the most potent class of all (Amoroso, et al., 2002). Fusion/entry inhibitors and Integrase inhibitors are newer classes of antiretroviral drugs. The NRTIs include Zidovudine (AZT or ZDV), Stavudine (d4T), Lamivudine (3TC), Emtricitabine (FTC), Zalcitabine (ddC), Abacavir and Didanosine (DDI). The nucleotide reverse transcriptase inhibitor includes Tenofovir. The NNRTIs consist of Efavirenz, Nevirapine and Delaviridine while protease inhibitors include Indinavir, Nelfinavir, Saquinavir, Ritonavir, Lopinavir, and Amprenavir. Two NRTIs are usually used in combination with one of the NNRTIs or a PI and this combination is called “highly active antiretroviral therapy”. Whichever combinations are used the principles of antiretroviral therapy are to preserve immune function, to reduce HIV-related morbidity and mortality, to ensure maximal suppression of viral replication, to preserve future treatment options, minimize toxicity and reduce HIV transmission (Amoroso, et al., 2002).

As a result of the effort to improve the quality of life and prolong the lives of PLHIV, the global roll-out of HAART has led to a reversal of the declining life expectancies in various countries. By 2008, the United States Presidential Plan for

AIDS Relief (PEPFAR), the Global Fund for AIDS, Tuberculosis and Malaria, and World Health Organization (WHO) 3 by 5 Initiative programs had initiated over four million people on HAART (World Health Organization, United Nations Children's Fund, & UNAIDS, 2009). This constituted a 10-fold increase from the 400,000 PLHIV who were on HAART in 2003. The greatest increase (30-fold) was seen in Sub-Saharan Africa, where an estimated 2.9 million PLHIV were on HAART by the end of 2008. Just under 73% of HAART recipients were in Sub-Saharan Africa, 14% were in East, South and South East Asia, 11% in Latin America, 2.1% in Europe and Central Asia, and 0.2% from North Africa and the Middle East (World Health Organization, et al., 2009). Recent estimates for high-income countries indicate that about 700,000 PLHIV are on HAART (World Health Organization, et al., 2009).

2.2 HIV Epidemic in Sub-Saharan Africa

Sub-Saharan Africa, a politically defined region which consists of all regions in Africa except North Africa, is the most severely region in the world affected by the HIV epidemic. In 2009, UNAIDS estimated that of the 33.3 million HIV-infected people globally, 22.5 million were in Sub-Saharan Africa with the majority of them in the reproductive age group (UNAIDS, 2010). Sixty-seven percent of the total number of HIV-infected people, that is, two out of three HIV-infected people worldwide, resides in Sub-Saharan Africa; 72% of deaths due to AIDS in 2009 occurred in this region. Sub-Saharan Africa had an estimated adult prevalence of 5.0% in 2009, compared to an adult prevalence of 0.2% in the Middle East and North Africa, 1% in the Caribbean, 0.8% in Eastern Europe and Central Asia and 0.5% in North America. The incidence of HIV declined from 2.2 million in 2001 to 1.8 million in 2009, but the number of PLHIV increased, mainly due to the decreased number of deaths following the roll-out of HAART throughout the continent (UNAIDS, 2010). Despite this roll-out, AIDS remains a major cause of mortality in the region (UNAIDS, 2007a) and concerted efforts are needed to further decrease the incidence of HIV infection in Sub-Saharan Africa.

In 2008, of the 430,000 new global cases of HIV among children below the age of 15 years, 390,000 (90.6%) cases occurred in Sub-Saharan Africa (UNAIDS, 2009). In 2009, due to increased access to PMTCT services, the number of children estimated

to be newly infected was 370,000 (UNAIDS, 2010). Though the number is less than the 460,000 newly-infected cases in 2001, it reveals a very high number of children being infected with HIV, despite proven strategies to prevent HIV transmission from mother to child. Though HAART coverage has increased in Sub-Saharan Africa, it has increased less so for children and therefore many children will die of their affliction before they are able to access life-prolonging therapy. Deaths among HIV-infected children had increased from 330,000 in 2001 to 360,000 in 2005, but declined to an estimated 330,000 in 2007 (UNAIDS, 2007a).

Unique to Sub-Saharan Africa is the high proportion of women and girls affected by the epidemic in comparison to other regions, where a higher proportion of men are affected by the epidemic. In this region, over 60% of PLHIV are female (Garcia-Calleja, Gouws, & Ghys, 2006). In some countries in the Sub-Saharan Africa region, young women aged 15-24 years are up to five times more likely to be infected than males of the same age group (UNAIDS, 2009). Women's vulnerability to HIV infection in Sub-Saharan Africa is attributed to biological as well as social, cultural and economical factors. Cross-generational relationships, a term used to define relationships where partners' ages differ by at least ten years, are also thought to increase the vulnerability of younger women to HIV, as they may not be capable of negotiating safe sex with older men (Leclerc-Madlala, 2008).

There is heterogeneity of the epidemic globally but particularly in Sub-Saharan Africa. Wilson (2006) divides Africa's HIV epidemics into four distinct clusters:

- Southern Africa where many countries have a very high HIV prevalence, ranging from 15-35%;
- East African countries (including Uganda) where the prevalence ranges from 2-7%;
- West African countries where prevalence ranges between 1-5%; and
- North Africa where HIV prevalence hardly ever exceeds 0.1%.

Southern Africa has the highest number of PLHIV with an adult HIV prevalence as high as 23.2% in Lesotho and 26% in Swaziland (UNAIDS, 2009) and the highest number of PLHIV in the world living in South Africa (UNAIDS, 2008). West and

Central African countries have a lower HIV prevalence than countries in East and Southern Africa, with some countries such as Niger and Senegal having HIV prevalence below 1% (UNAIDS, 2009).

East Africa has seen a declining HIV prevalence in some countries, but a stabilisation of the epidemic in other countries such as Uganda (Wabwire-Mangen, Odiit, Kirungi, Kisitu, & Wanyama, 2009). Southern and East Africa also have one of the highest coverage of antiretroviral programs at 48%, compared to West and Central Africa at 30%. In fact, in 2008, there were an estimated 2,395,000 PLHIV on HAART in East and Southern Africa: of these, 2,200,000 were adults above 14 years of age; while only 195,100 PLHIV aged between 0-14 years were on HAART (World Health Organization, et al., 2009).

Transmission of HIV in Sub-Saharan Africa

Heterosexual transmission and MTCT of HIV remain the two major modes of transmission in Sub-Saharan Africa. In Sub-Saharan Africa, stable and reportedly mutually monogamous relationships were for a long time considered as being 'low-risk' for HIV transmission. However, now a high proportion of people living in such relationships are infected with HIV. In Lesotho and Kenya, 62% and 44% of incident cases occur among people in stable, monogamous relationships (UNAIDS, 2009). High levels of sero-discordant partnerships occur in Africa, with over 44% of PLHIV in Kenya having a partner who is not infected with HIV (UNAIDS, 2009) and a high level of transmission occurs among these HIV discordant couples. In a large HIV-1 prevention trial in Africa involving 3408 HIV-1 discordant couples from 12 sites in Eastern and Southern Africa, HIV discordance in the various sites ranged from 36-85%, with an overall rate of 49% (Korenromp et al., 2002). This meant that among all couples tested who had at least one HIV-1 infected partner, almost 50% had an HIV-negative spouse. In addition to this, high levels of multiple sexual partners also continue to be documented in some Sub-Saharan countries, with 29% of Ugandan men aged 15-49 years reporting having more than one sexual partner in 2005 (Opio et al., 2008). This remains of concern, especially since there is a low use of condoms in the region (UNAIDS, 2009).

Recent evidence points to the increasing contribution to the HIV epidemic in Sub-Saharan Africa by MSM and IDUs. HIV epidemics that had previously been considered predominantly heterosexual in nature in Africa have been found to be more heterogeneous, with a high HIV prevalence among MSM (Beyrer, et al., 2010). In Ghana, unlike other countries in the West African region, the HIV prevalence among MSM is 15 times higher than in the general population and men-to-men HIV transmission is actually the predominant mode of HIV transmission (Beyrer, et al., 2010). Even in other African countries where there are generalised and mature epidemics, MSM are more likely to have HIV than the general population: up to four times more likely in Nigeria and seven times more likely in Sudan (Beyrer, et al., 2010). In 2006, almost 30% of new infections in Kenya occurred among sex workers and their clients, MSM, and IDUs, but there were limited intervention programs targeting these high-risk groups (Gelmon, Kenya, Oguya, Cheluget, & Haile, 2009). High levels of stigmatisation and criminalisation of same-sex relationships have led to very low allocation of resources for combating the spread of HIV among MSM in Sub-Saharan Africa.

Though IDUs are still a small population of PLHIV in Africa, it is believed that they have the potential to contribute significantly to the HIV epidemic because of their high-risk sexual and injecting behaviours (Dewing, Pluddemann, Myers, & Parry, 2006). The HIV prevalence rates among IDUs in Kenya have been found to be as high as 53% (Odek-Ogunde, 2004). What is more significant is the high rate of sharing needles, limited access to clean or sterile injecting equipment, low rates of condom use, and low knowledge of HIV among IDUs as well as the spread of intravenous drug use from major cities and towns to rural areas (Beckerleg, Telfer, & Lewando, 2005). Thus IDUs are a bridging population in some mature epidemics and are thought to be capable of worsening already dire situations.

Monitoring of the HIV epidemic in Sub-Saharan Africa

While HIV surveillance in Sub-Saharan Africa continues to improve, there are still many gaps especially in determining the prevalence among high-risk groups. HIV surveillance is necessary for determining global and regional trends of the epidemic, the burden of HIV disease, areas for resource allocation, and impact of national interventions and strategies (Lyerla, Gouws, & Garcia-Calleja, 2008). Initially HIV

sero-surveillance relied on antenatal clinic (ANC) sentinel surveillance of pregnant women in their reproductive ages. While ANC surveillance previously provided important information on the trends of the HIV epidemic, it has not been a reliable method of determining the state of the general population epidemic, especially in regions with mature epidemics and low use of contraception. HIV-infected women are less represented in antenatal clinics, because their fertility is affected by several social, behavioural and biological factors. As a result, in some countries in the Sub-Saharan region, the HIV prevalence data from antenatal sites is an underestimation of the trends of HIV prevalence in the general population (Fabiani, Fylkesnes, Nattabi, Ayella, & Declich, 2003). Though national HIV program managers rely on estimates that are valuable for determining allocation of resources, it is essential that they carefully analyse their local epidemics, the dynamics of the spread of the infection, the social conditions that determine the local epidemic and then determine what needs to be done to prevent the further spread of HIV (UNAIDS, 2007b).

Furthermore, since 2001 several population-based household surveys have been conducted in selected African countries to supplement sentinel surveillance data in order to better estimate population-based HIV prevalence data. These surveys have led to a revision of HIV-prevalence estimates in several countries (Wilson, 2006). For instance the population-based estimates in almost 19 countries, including Rwanda and Ethiopia, were lower than the antenatal estimates. In Sierra Leone, Burkina Faso and Ghana, population-based estimates were between two- and five-fold lower than antenatal estimates (Wilson, 2006). It was only in Uganda that population estimates were higher than antenatal estimates. Accurate estimation of HIV prevalence is necessary for appropriate allocation of resources for control of the HIV epidemics in these countries.

Lyerla et al. (2008) found that of 44 countries in Sub-Saharan Africa, a region with many countries with generalised epidemics, 24 (55%) had fully functioning surveillance systems which were timely, of adequate frequency and able to capture both rural and urban populations. They were relatively consistent, able to capture data from the same sites over time, and adequately covered the populations at risk for HIV. In addition, several Modes of Transmission Analyses (MoT) have been performed in Uganda, Kenya, Lesotho, Mozambique, Swaziland and Zambia. The

MoT also assessed national prevention strategies and their relationship to the documented risk behaviours and the epidemiology of HIV infection. The syntheses of epidemiological and programmatic data allow program managers to determine the magnitude of their epidemics and appropriate resource allocation (UNAIDS, 2009).

2.3 HIV Epidemic in Uganda

Background of HIV epidemic in Uganda

The first AIDS cases in Uganda were diagnosed in 1982, in Rakai District (Wabwire-Mangen, Opio, Tumwesigye, Asingwire, & Bukuluki, 2006). Initially known as '*Slim*' because of the severely emaciated state of its victims, AIDS quickly spread, first along truck routes and then to the rest of the country. By the late 1980s, the HIV epidemic had spread to all parts of the country, and affected people from different walks of life, regions and age groups. The HIV epidemic in Uganda is now classified as generalised, mature and severe (Uganda AIDS Commission, 2007) and it is estimated that approximately one million people are infected with HIV, with the highest number of people in the 15-49 years age group.

UNAIDS (2006) estimated that by the end of 2005, Uganda had an adult HIV prevalence rate of 6.7%. Women aged 15-49 years constituted 52% of the total population of HIV-infected people in Uganda and 110,000 were children below the age of 15 years. Among young people aged 15-24 years, 2.3% of males and 5.0% of females were infected with HIV (UNAIDS, 2006). The epidemic in Uganda is heterogeneous, affecting different sub-populations in different geographical, socio-economic and socio-demographic groups. The major routes of transmission are heterosexual contact and MTCT, while MSM and IDUs are estimated to contribute to less than 1% of transmission (Wabwire-Mangen, et al., 2009).

The HIV epidemic has had a severe impact on the Uganda community. The cumulative number of deaths is estimated at 900,000 and the current life expectancy is 48 years (Uganda AIDS Commission, 2007). HIV is also responsible for up to 20% of all deaths and is one of the leading causes of death among people aged 15-49 years. A high number of admissions in hospitals are related to HIV infection and it has caused a resurgence in the number of people infected with tuberculosis (TB). The

country also has over a million children orphaned by AIDS, with many children becoming heads of households at a very young age (Ministry of Health Uganda & ORC Macro, 2006; Uganda AIDS Commission, 2007).

Epidemiology of the HIV epidemic in Uganda

The epidemic in Uganda has been characterised by three main phases (Uganda AIDS Commission, 2007). The first phase, which lasted from about 1982 to 1992, consisted of a rapid increase in the number of HIV infections, with a peak of 30% HIV prevalence in some ANC sentinel surveillance sites (Wabwire-Mangen, et al., 2009). The second phase was characterised by a sharp decline in number of new infections and the overall HIV prevalence; this phase lasted until about 2000. These declines in prevalence and incidence mainly resulted from changes in sexual behaviour, particularly a reduction in the number of sexual partners and increases in condom use with casual sexual partners (Asiimwe-Okiror et al., 1997; Corey, Wald, Celum, & Quinn, 2004; Kirungi et al., 2006). The third phase has seen both a stagnation in the prevalence of HIV (between 6.1% and 6.5%) in some antenatal surveillance sites, and an increase in the incidence of HIV in others (Wabwire-Mangen, et al., 2009).

The epidemic is not homogenous across Uganda and it differs by geographical region, age, sex and marital status (See Table 3). According to the Uganda HIV/AIDS Sero-Behavioural Survey 2004-2005, Kampala, Central and the North Central regions had the highest HIV prevalence, with females having a higher HIV prevalence than males, especially in the 15-34 years age group (Ministry of Health Uganda & ORC Macro, 2006). The sex difference in prevalence only decreased in the 35-39 years age group. Urban residents had a higher HIV prevalence than rural residents, while widowed respondents had the highest HIV prevalence (possibly related to the fact that their spouses may have died of HIV), followed by divorced Ugandans.

Although it has been relatively easy to monitor HIV prevalence in Uganda, measurement of both HIV incidence and the attribution of each risk group to the overall HIV incidence are more problematic. In comparison to prevalence, incidence

Table 3: HIV prevalence by characteristic in Uganda, 2004-2005

Characteristic	Prevalence (%)
Regions	
Kampala	8.5
North Central Uganda	8.2
Central	8.5
West Nile (North West)	2.3
North East	3.5
East Central	6.5
Eastern	5.3
Western	6.9
South West	5.9
Sex	
Male (total)	5.2
Female (total)	7.2
Residence	
Urban	10.1
Rural	5.7
Marital status	
In stable union	6.3
Widowed	31.4
Separated	13.9
Single	1.6

Source: HIV/AIDS Sero-Behavioural Survey 2004-2005 (Ministry of Health Uganda & ORC Macro, 2006)

is a more reliable measure of the epidemic and reflects the impact of prevention efforts. HIV prevalence can be affected by mortality rates, migration and survey coverage, so incidence is a better reflection of the trend of an epidemic and its size (Mbulaiteye et al., 2002). A ten-year longitudinal study conducted by the Medical Research Council (MRC) in rural Southwest Uganda measured the incidence and prevalence among adults aged 13 years and over and found significant declines in

incidence over this time period. There was a steady fall in HIV-1 incidence from 8.0 cases per 1000 person years at risk (PYAR) in 1990 to 5·2 per 1000 PYAR in 1999 (p=0·002, chi square for trend). There was also a decrease for both women and men: 6·4 per 1000 PYAR to 4·4 per 1000 PYAR [p=0·03]; and from 9·7 per 1000 PYAR to 6·0 per 1000 PYAR [p=0·045], respectively. For people aged between 13 and 35 years, the incidence fell from 7·2 per 1000 PYAR to 7·0 per 1000 PYAR [p=0·04], while for those aged above 35 years, the incidence fell sharply from 9·2 per 1000 PYAR to 2·0 per 1000 PYAR [p=0·008] (Mbulaiteye, et al., 2002).

A more recent study has shown that the initial decline in the total HIV prevalence and incidence has now been reversed. A study carried out between 1989 and 2005 in rural south-western Uganda (Shafer et al., 2008) showed a decline in HIV incidence and prevalence in the 1990s but an increase in prevalence and stabilisation of incidence in the early 2000s. Of note was that the HIV prevalence remained higher among females than males, and that the incidence was consistently higher in males aged 25-29 years and females aged 20-24 years. The increase in the HIV incidence among males aged 40-44 years was also notable (Shafer, et al., 2008).

The Uganda AIDS Commission (2007) estimated that there were 132,500 new cases in 2005. Wabwire-Mangen et al. (2009) estimated that there were a total of 91,546 new adult HIV infections in Uganda in 2008: the highest number of new infections occurred among persons in mutually monogamous relationships (39,261), followed by those involved in multiple partnerships (21,722) and then those in partnership with those in multiple partnerships (19,925). These are only estimations, as no recent incidence studies have been conducted to determine the actual trends of the epidemic.

These trends in prevalence and incidence in Uganda coincided with increases in risky sexual practices (Opio, et al., 2008). Between 1997 and 2005, there was a decrease in the proportion of young people aged 13-34 years using condoms with casual sexual partners: from 51.3% to 48.7 % among 13-19 year olds, from 74.1% to 50.7% among 20-24 year olds and from 63.8% to 58.6% among 25-34 year olds. Even though there was an increase in the proportion of older people using condoms with casual sexual partners, the overall proportions remained low: in 2005, only 44.8% of 35-44 year

olds and 24.4% of those aged above 44 years were using condoms with casual sexual partners. Of concern, a study found that there was a general increase in the proportion of older men with one or more casual sexual partners, especially among the 35-44 year olds in a cohort in rural south-west Uganda between 1997 and 2006 (Biraro et al., 2009). Furthermore, in 2005 a high proportion of young people in Uganda ever had sex at early ages: by 18 years of age, 61% of females and 40% of males had ever had sex (Shafer, et al., 2008).

Though heterosexual transmission remains the major route of transmission in Uganda, the dynamics have changed over the last two decades. The MoT analysis conducted by the Uganda AIDS Commission and UNAIDS revealed that transmission in long–term stable relationships has increased, and the peak HIV prevalence has shifted to older age groups. The highest prevalence among males is in the 35-39 years age group, while it is in the 30-34 years age group for females (Wabwire-Mangen, et al., 2009). While the HIV epidemic is generalised in Uganda, there are some populations also known as 'most-at-risk-populations' (MARP) which are particularly vulnerable to the HIV epidemic. These include CSWs, fishing communities, members of the armed services, people in conflict areas (especially internally displaced persons (IDPs), and people with disabilities (Uganda AIDS Commission, 2007). Their vulnerability is due to both individual behaviours, and structural factors that increase their risk of contracting HIV, such as poverty, mobility, and lack of access to prevention and curative services.

Prevalence among CSWs is almost seven times higher than the general population and they remain an important bridging population with the general population. The fishing communities have been found to be particularly vulnerable to the spread of HIV because of lack of HIV prevention services and the precarious nature of their work. Like armed service men, many fishermen experience long spells of time away from home and take on multiple long-term partners in various towns and villages. However, despite the existence of these vulnerable populations, HIV transmission among people in stable unions is a major cause of new infections, with up to 65% of new infections estimated to be occurring in these unions (Uganda AIDS Commission, 2007). This indicates the importance of controlling infections through all populations and not just those thought to be at higher risk.

Mother-to-Child transmission of HIV in Uganda

Mother-to-child transmission of HIV remains one of the major routes of HIV transmission in resource-poor countries, and the greatest cause of infection in children below the age of 15 years (World Health Organization, 2006). Though the number of children newly infected with HIV has decreased, the continued infection of children reflects the inadequate coverage of the PMTCT programs as well as the low effectiveness of those programs already in place. Though WHO (2009) documented an increase in PMTCT services from 10% in 2004 to 45% in 2008, the coverage of PMTCT services, i.e. the conventional provision of ART prophylaxis to HIV-infected pregnant mothers, remains inadequate.

About 21% of HIV cases in Uganda are believed to result from MTCT (Uganda AIDS Commission, 2007). In 2008, it was estimated that there were at least 20,200 new infections among children in Uganda (Wabwire-Mangen, et al., 2009). Mother-to-child transmission of HIV continues despite the wide dissemination of information on how HIV is transmitted and the availability of interventions to reduce transmission. The continued and steady growth of the HIV epidemic does not arise primarily from deficiencies in scientific knowledge or from a lack of effective strategies. Rather, it results from a failure to use the highly effective tools that are available to slow down the spread of HIV and to deliver them with sufficient intensity and adequate coverage of the populations most in need (UNAIDS, 2007b).

In Uganda, PMTCT activities include HIV testing and counselling of pregnant women in antenatal clinics, provision of antiretroviral drugs to HIV-infected women and infants exposed to HIV infection, and counselling on modification of infant feeding methods (Ministry of Health [Uganda], 2003). Although preventing unintended pregnancy among HIV-positive women is an effective approach to reducing paediatric HIV infections and is vital in meeting HIV-positive women's sexual and reproductive health needs (WHO/UNFPA/UNAIDS/IPPF, 2005), it remains one of the most under-utilised strategies, mainly because of inadequate access to family planning methods (Nakayiwa, et al., 2006). The other UN-recommended interventions to prevent HIV among infants and young children include primary prevention of HIV among women of childbearing ages, preventing

HIV transmission from women living with HIV to their infants and providing appropriate treatment, care and support to women living with HIV, their children and families (World Health Organization, 2007).

Risk factors for transmission of HIV in Uganda

In order to fully understand an HIV epidemic, the risk factors that perpetuate the spread of the infection must be understood. Risk factors are defined as "an aspect of personal behaviour or life-style, an environmental exposure, or an inborn or inherited characteristic, which on the basis of epidemiologic evidence is known to be associated with health-related condition(s) considered important to prevent" (Last, 2001). In the HIV context, risk factors include injecting drug use, unprotected sexual intercourse, and multiple concurrent long-term partners with low and inconsistent condom use. In Uganda, the risk factors for HIV transmission include multiple concurrent sexual partners, discordance and non-disclosure of HIV status, lack of condom use, transactional sex, cross-generational sex, presence of STIs, intact penile foreskin, alcohol and drug use, and behavioural disinhibition due to availability of HAART (Wabwire-Mangen, et al., 2009).

Although having multiple sexual partners is one of the major risk factors for HIV transmission in Uganda, sexual concurrency is thought to be a particularly important factor in both the transmission of HIV and the explanation of the high rates of HIV infections (Morris, Hunter, & Wawer, 2006). Sexual concurrency, being any kind of sexual overlap within a period of time, includes any form of polygamy, having long-term sexual partners who have other sexual liaisons (even brief ones), or even very sporadic sex with partners in several locations (Mah & Shelton, 2011). The person with multiple sexual partners in this situation serves as a conduit between sexual partners. The higher the level of concurrency, the higher the possibility of transmission between different sexual partners, with transmission reliant on the timing and the sequencing. In Uganda, large numbers of adult males and females still report having more than one sexual partner. Among women aged 15-49 years, 3.8% reported having two or more sexual partners in the last 12 months, and this was higher among females aged 15-19 years (7.6%). The proportions were even higher among males aged 15-49 years: 29.3% of them had had two or more sexual partners

in the last 12 months, with 31.6% of the males in the 30-39 years age group having two or more sexual partners (Ministry of Health Uganda & ORC Macro, 2006).

HIV-serodiscordance is also another factor that drives the spread of infection, especially in mutually monogamous relationships. The Uganda Behavioural Survey found that about 5% of 3,896 cohabiting couples were HIV-sero-discordant, that is, one partner was infected with HIV while the other was not (Ministry of Health Uganda & ORC Macro, 2006). There is a low use of condoms in these relationships and a lack of disclosure, both of which put the non-infected partner at risk of infection. There is also a lack of knowledge regarding the possibilities of sero-discordance, with over 70% of both men and women thinking that if one partner has HIV, then inevitably the other partner does as well (Ministry of Health Uganda & ORC Macro, 2006). This makes people reluctant to test themselves or even protect themselves from infection. In a study of HIV-infected people in Uganda and their spouses, 43% of spouses were found to be HIV negative and yet 99% of them had never tested themselves for HIV (Were et al., 2006).

Cross-generational and transactional sex are also factors for the spread of HIV in Uganda (Wabwire-Mangen, et al., 2009). Cross-generational sex refers to sex with someone at least ten years older, while transactional sex refers to sex in exchange for money or gifts. Sometimes these forms of sex overlap whereby older men have sex with younger women in exchange for money or gifts. In both types of sex there is usually an element of exploitation, especially when there is age, economic and social disparity. In situations of cross-generational or transactional sexual relationships, younger people are not able to negotiate use of condoms and this exposes young people to HIV (Wabwire-Mangen, et al., 2006). This may explain the higher HIV prevalence among young Ugandan women aged 15-24 years (5.0%) in comparison to males (2.3%) in the same age group (UNAIDS, 2006).

The relationship between bacterial and viral STIs and HIV transmission has been well documented, though the strength of association varies by STI organism, population and phase of the STI and HIV epidemics (H. Ward & Ronn, 2010). Biological studies have been supported by ecological, cross-sectional, case-control and cohort studies which have all demonstrated that infection with STIs enhances the

transmission of HIV. Although associations have been found between HIV transmission and STIs such as gonorrhoea, chlamydia, trichomoniasis, bacterial vaginosis, Human Papilloma Virus (HPV) and lymphogranuloma venereum (LGV) (Ronn & Ward, 2011), Herpes Simplex Virus, Type 2 (HSV-2) as well as other ulcerative STIs have the strongest association with the sexual transmission of HIV.

The ulcerative STIs are thought to increase the infectiousness of the infecting individual as well as the susceptibility of the recipient (Piot & Bartos, 2002). HSV-2 is one of the major causes of genital ulcer disease in both developed and developing countries and there is a close link between the HIV epidemic and HSV-2 epidemic (Corey, et al., 2004). In Sub-Saharan Africa, HSV-2 causes up to 35% of the population-attributable risk of HIV acquisition (H. Ward & Ronn, 2010). HIV incidence has been found to increase with HSV-2 prevalence and HIV-1 prevalence increases HSV-2 incidence. In addition, both viruses change the natural history of each other as determined by biological experiments and observations of mucosal disruption by HSV-2 and the resultant susceptibility to HIV. HSV-2 reactivation also leads to an increased influx of activated CD4-bearing lymphocytes in the genital tract, which are known target cells for HIV. These two processes increase the chance that exposure to HIV would result in infection (Corey, et al., 2004).

A systematic review of 19 longitudinal studies conducted worldwide found that there was an increased risk of HIV among people infected with HSV-2, with a relative risk of 2.7 (95% CI: 1.9-3.9) for men and 3.1 (95% CI: 1.7-5.6) for women in comparison to the general population (Freeman et al., 2006). A high STI prevalence has been documented in Uganda, with over 74% of women and 57% of men in Rakai found to have HSV-2, a factor that increases their risk of HIV acquisition (Corey, et al., 2004). According to the Uganda Sero-Behavioural Survey (Ministry of Health Uganda & ORC Macro, 2006), 44% of people aged between 15-49 years of age were positive for HSV-2, with the prevalence increasing with age for both males and females. Seventy-five percent of females aged 45-49 years were positive for HSV-2, compared to 21% of 15-19 year olds. Conversely, the suppression of HSV-2 by acyclovir treatment does not lead to a reduction in the transmission of HIV (Auerbach, Parkhurst, Cáceres, & Keller, 2009; Sullivan, et al., 2009; Wabwire-Mangen, et al., 2006). The failure of STI intervention trials to control HIV

transmission may be due to a lack of compliance, low population coverage, inadequate suppression levels, or differences in the epidemic phases of both HIV and HSV-2 epidemics, all of which warrant further investigation (H. Ward & Ronn, 2010).

The link between an intact penile foreskin and HIV transmission has also been extensively examined (H. A. Weiss, Quigley, & Hayes, 2000). Ecological and epidemiological studies, as well as biological theories related to the role of penile Langerhan cells in the transmission of HIV, all support the proposition that male circumcision protects against HIV infection. These receptor cells in the foreskin increase the vulnerability of an uncircumcised man to acquisition of the virus (Siegfried et al., 2003). These studies were further supported by three randomised control trials (RCTs) that confirmed the protective role of male circumcision against HIV transmission. Pooled analysis from three studies from Uganda, Kenya and South Africa indicated a risk ratio of 0.44 (95% CI: 0.33– 0.60, P<.0001), i.e. there was statistically significant protection against HIV infection among those males who were circumcised compared to those who were not circumcised (Mills, Cooper, Anema, & Guyatt, 2008). Thus the low level of circumcision in Uganda, only at 25% based on the Behavioural Survey, is postulated to be one of the major factors responsible for continued HIV transmission (Wabwire-Mangen, et al., 2009).

In Uganda there are certain occupations that are associated with greater risks of transmission of HIV (Uganda AIDS Commission, 2007). These include CSWs, truck drivers, people working with the armed forces, alcohol brewers and sellers, and fishermen. The high risk of acquiring HIV is attributable to their mobility and patterns of sexual behaviour, i.e. multiple concurrent sexual partnerships and the lack of condom use (Uganda AIDS Commission, 2007). People from fishing communities are seen to be at particularly high risk because of their mobility, time spent away from home, the cash economy in which they work, their young age groups as well as availability of CSWs in their fishing communities (Wabwire-Mangen, et al., 2006).

Drivers of the HIV epidemic in Uganda

In addition to the individual factors that sustain the epidemic in Uganda, there are also social, economic and structural factors that continue to drive the epidemic.

These factors, also known as 'drivers' are equally important and must be addressed as part of the overall strategy to control the spread of the infection. The relationship between HIV and these social drivers are complex and are not linear or one-to-one relationships that can be tested. Social drivers are seen to act at various levels and include various biological, behavioural, social, and psychological factors. They all influence the context in which HIV transmission occurs and the context in which it can be prevented (Auerbach, Parkhurst, & Caceres, 2011; Auerbach, et al., 2009). These contextual factors include a wide disparity in wealth, the low social, economic and cultural status of women, which makes them vulnerable to HIV acquisition, and high levels of stigma and discrimination that prevent PLHIV from accessing services (Wabwire-Mangen, et al., 2009). Factors such as poverty, gender inequality and human rights violations increase the vulnerability to HIV infection at both individual and community levels (UNAIDS, 2007b).

Sociocultural factors are also thought to impact on the transmission of HIV in various ways. Early sexual debut and early marriage, especially of younger women to older men in some Ugandan communities, are thought to be contributing factors to the higher HIV prevalence in younger women in comparison to males of the same age. Cultural values and traditional gender roles, as well as economic vulnerability of women and girls, increase their vulnerability to HIV transmission. Power differences between women and men prevent women from asking their spouses to use condoms or other preventive measures to protect themselves from HIV. Women are not expected to refuse their husbands' sexual advances and there is little or no communication or negotiation about sex within marriage (Wabwire-Mangen, et al., 2006).

Wealth and poverty have a dialectical relation with HIV transmission. Wealth is thought to provide wealthy people with an opportunity to take advantage of those less wealthy. Wealthier people may indulge in more sexual practices and have more sexual partners. Poor people may resort to commercial sex, transactional sex or cross-generational sex, which puts them at risk of acquiring HIV (Wabwire-Mangen, et al., 2009). According to the Uganda Sero-Behavioural Survey (Ministry of Health Uganda & ORC Macro, 2006), the HIV prevalence increased from the lowest to the highest wealth quintile for both males and females: from 5% to 11% among females

and from 4% to 6% among males. Therefore the relationship between poverty/wealth and HIV is about the context in which it occurs, and its impact on sexual arrangements and vulnerability (Auerbach, et al., 2009). While both wealth and poverty increase the risk to HIV, the wealthy have the power to negotiate safe sex (if they so desire), but the poor have less power to do so.

Unfortunately, high levels of stigma and discrimination also contribute to the further spread of HIV. Stigma prevents PLHIV from accessing health services and it may also discourage those at risk of acquiring HIV from accessing preventive services. PLHIV may fear using known risk-reduction behaviours including abstinence, partner limitation, and correct condom use (UNAIDS, 2007b). Similarly, HIV-infected mothers who are breastfeeding may be reluctant to use replacement feeding because they are fearful of stigma and discrimination. Disclosure of HIV status to sexual partners may also be hampered.

The Uganda National AIDS Prevention and Control Policies

Uganda is considered to be one of the earliest and best success stories in relation to the control of the HIV epidemic. In response to the epidemic, the Government of Uganda (GoU) set up several AIDS Control Task Forces and Programs to provide strategies and policies aimed at containing the spread of the infection. In 1986, the first National AIDS Control Program (ACP) was established by the Ministry of Health (MOH). In 1987, the first National Task Force was established and in 1992, the Uganda AIDS Commission (UAC) was established (Wabwire-Mangen, et al., 2006). The UAC's role included planning, coordination, and monitoring of the national strategy against HIV, ensuring implementation of all activities, and mobilising resources for implementation. Uganda has had policies for the control and prevention of HIV since the 1980s and the five-year National Strategic Plans (NSP) since 1986. These policies and accompanying guidelines on voluntary counselling and testing (VCT), PMTCT, ART, condom use, and orphans and vulnerable children (OVC), have been essential in guiding all stakeholders in the strategies required for the management of patients, people at risk of HIV, and mitigation of the epidemic (Uganda AIDS Commission, 2007).

Uganda's response to the epidemic has always been multi-sectoral and multi-level involving government, community and religious leaders. Political commitment from the highest levels of government from the 1980s enabled a robust mobilisation of all sectors and communities to help combat the spread of the infection (Wilson, 2006). Equally important was the establishment of community organisations such as The AIDS Support Organisation (TASO) in 1988, research centres such as the Joint Clinical Research Centre (JCRC) in 1990, testing sites including the AIDS Information Centre (AIC) in 1991. The establishment of these bodies not only provided care and support to AIDS patients and people at risk of acquiring HIV, but also represented a broad approach to the control efforts. Key elements of the Ugandan response also included the active participation of religious leaders and institutions in the prevention and management of HIV, together with the dissemination of information and the mitigation of stigma (Corey, et al., 2004).

Other measures used in the control and prevention of the HIV epidemic in Uganda included information dissemination and educational campaigns to promote the Abstinence, Being Faithful and Condom program, known as the 'ABC' approach to HIV prevention. Information, Education and Communication (IEC) programs to encourage behaviour change were a major element of the National AIDS Strategy. Strong messages such as "Beware of AIDS, AIDS Kills!" and "Love Carefully or Love Faithfully" were commonly used to drive change in sexual behaviour (Wabwire-Mangen, et al., 2006). It is thought that these programs, particularly those that focused on sexual behaviour change (especially partner number reduction), were instrumental in the decline of the HIV prevalence in Uganda in the 1990s (Wilson, 2006). Life skills education, through programs such as School Health Education Project and Straight Talk, reached over a million young people to encourage delayed sexual debut and development of life skills. These youth-targeting programs promoted the delay of sexual debut, abstinence, reduction in the number of sexual partners, and use of condoms. It is believed that they had a significant impact on the reduction in both HIV incidence and prevalence in Uganda (Corey, et al., 2004).

Promotion of condom use intensified during the 1990s and resulted in significant increases in the number of men and women using condoms, especially in casual sexual relationships. According to the Uganda HIV/AIDS Sero-Behavioural Survey

2004-2005 (UHSBS) (Ministry of Health Uganda & ORC Macro, 2006), 16% of men and 9% of women who had had sex in the prior 12 months reported that they had used a condom during their last sexual encounter. These percentages were higher among the 15-19 years age group, those who had never married, people who lived in an urban area, and those who were better educated or were in the highest wealth quintile. Among those whose last sexual encounter was with a non-stable partner, 47% of women and 53% of men reportedly used a condom. This is particularly important considering the high risk of contracting HIV from casual sexual partners.

Uganda has also had a marked increase in key HIV-related services, especially VCT and PMTCT interventions. There has been a significant increase in the number of adults who have ever tested for HIV: from 4% in 2001 to 21% in 2006 (Wabwire-Mangen, et al., 2009). VCT is considered an essential service that allows people to know their HIV status and is an entry point for HIV care and support services. People who know their HIV status are more likely to protect themselves and others from infection or re-infection (Wabwire-Mangen, et al., 2006). Antiretroviral therapy has been implemented across Uganda and over 160,000 people were estimated to be on HAART in 2008. This was the eighth highest number of PLHIV on HAART in the world (World Health Organization, et al., 2009) and Uganda intends to increase this number to 240,000 by 2012 (Uganda AIDS Commission, 2007).

PMTCT services also allow HIV-infected women to know their status so that they can access services early enough so as to prevent transmission of infection to their infants. The PMTCT program has been essential in controlling the spread of HIV from mothers to their children. By the end of 2007, PMTCT coverage in Uganda was 29% and the number of facilities providing these services was 568 (Wabwire-Mangen, et al., 2009). These service points included hospitals and health centres (HC) at district, county, and parish levels. In Uganda the PMTCT programs provide VCT within the antenatal clinics, counselling on infant feeding, and modification of birth practices and administration of ART to HIV-infected mothers and their infants.

Research and surveillance activities have also been an important part of the control efforts and have included ANC surveillance activities, AIDS case surveillances, the surveillance of sexual health clinic attendees, Demographic Health Surveys, and

longitudinal behavioural and epidemiological studies. Trends in HIV prevalence have been monitored since 1987 (Corey, et al., 2004), enabling the government, ministries, and communities to understand not only the trends in the infection, but also the impact of various efforts to control the spread of infection. The national surveillance system established sentinel sites in both urban and rural regions in most regions in the country and enabled an extensive monitoring of the epidemic. By 2000 there were 15 sentinel sites across Uganda. In addition, the Medical Research Council (MRC) and the Rakai Health Services Program (RHSP) longitudinal epidemiological studies have provided invaluable and critical data for the monitoring of the epidemic and information on sexual behaviour over a long period of time. These two studies provided incidence data for the HIV epidemic in Uganda, together with vital information about the impact of national prevention efforts (Wabwire-Mangen, et al., 2006). Unfortunately, these two studies were limited in geographical coverage and therefore were unable to elucidate incidence trends in other parts of Uganda, for instance Northern Uganda.

Despite the positive aspects of Uganda's epidemic response, there are still many gaps. Only an estimated 21% of people in Uganda have tested for HIV (Wabwire-Mangen, et al., 2009) and yet more than 70% of adult Ugandans have expressed the desire to test for HIV (Uganda AIDS Commission, 2007). Over 50% of women cannot access PMTCT services. There are few programs for MSM and IDUs, and condoms are used in only about a half of casual sexual encounters. Other vulnerable groups also remain neglected, such as commercial sex workers, IDPs, fishing communities, and uniformed forces (Wabwire-Mangen, et al., 2006). There has also been a fall in the number of agencies providing IEC for behavioural change; some of the programs that resulted in behaviour change have not been sustained. As part of the ABC approach, there has been more emphasis on abstinence and behaviour change, and less emphasis on condom use. This approach, together with the inconsistent supply of condoms to the populations at risk and concerns about the quality of the condoms, are thought to have contributed to the lower use of condoms in the Ugandan population (Wabwire-Mangen, et al., 2006).

The number of people receiving HAART has increased but the overall coverage has remained low at 35.7% (Wabwire-Mangen, et al., 2009). The availability of HAART

is also believed to be fuelling a resurgence in risky sexual behaviour among both HIV-positive and negative people (Wabwire-Mangen, et al., 2006). There is also a need to link prevention services with HAART provision. In many regions VCT is not linked to HAART or PMTCT programs where further support and care can be provided to people testing positive for HIV (Wabwire-Mangen, et al., 2006).

The alignment of resources to where the most number of new infections are occurring is also important (Wabwire-Mangen, et al., 2009). Seventy-six percent of new infections are caused by sexual transmission and most of these (45-50%) are occurring among married couples or people in stable unions, while commercial sex counts for 10-20% and casual sex for 10-15% of new infections (Uganda AIDS Commission, 2007). MTCT counts for 24% of new infections. Thus, the allocation of resources should reflect the sources of the burden of new infections. Most interventions which were aimed at young unmarried couples are not suitable for controlling the transmission among HIV-discordant married couples (Uganda AIDS Commission, 2007). The Know Your Epidemic (KYE) and Know Your Response (KYR) component of the Uganda MoT study indicated that the greatest need for prevention was among people who were in mutually monogamous relationships, people who had multiple sexual partners and people who were at high risk such as CSWs, fishing communities, IDUs and MSM (Wabwire-Mangen, et al., 2009).

The most recent Ugandan National Strategic Plan (NSP) 2007/8-2011/12 (Uganda AIDS Commission, 2007) demonstrates the determination of the Ugandan Government and other stakeholders to reinvigorate the activities that are needed to further control the epidemic. The Plan aims to reduce the HIV incidence by 40%, to improve the quality of life of PLHIV, to mitigate the sociocultural and economic effects of the epidemic, and to build a strong, effective support system for the delivery of services (Uganda AIDS Commission, 2007). It identified three main thematic areas that include prevention, care and treatment, and social support, with each area having specific objectives and actions. Prevention activities include reinforcing activities among populations at high risk, scaling up of PMTCT programs, ensuring blood transfusion safety, and control of STIs. The Strategic Plan also set out strategies to increase the number of PLHIV on HAART and the number of people utilising HIV testing services, to implement actions for treatment and

prevention of TB, and to improve home-based care (HBC) of PLHIV. Social support strategies included psychosocial support, provision of formal, informal and vocational education to OVCs and other vulnerable populations, and improving food and nutrition security among PLHIV (Uganda AIDS Commission, 2007).

Government, communities and organisations working in the area of HIV prevention and control acknowledge that there needs to be a revitalisation of the HIV programs specifically targeting the groups at risk for infection. Broad programs unfortunately lead to situations where some people at risk for infection are not targeted to receive behaviour change messages or services in general. Despite the increase in provision of HAART, prevention remains the most important element in the control of the Ugandan HIV epidemic, with a need to improve and sustain these prevention programs (Wilson, 2006).

2.4 HIV Epidemic in Northern Uganda

Northern Uganda, like other areas of Uganda, has been severely affected by the HIV epidemic. Inaccessibility to most of the areas during the civil conflict made it impossible to have an accurate picture of the epidemic and knowledge concerning what the risk factors for transmission were. Data from St. Mary's Hospital, Lacor, one of the antenatal sentinel sites for HIV surveillance, showed that the HIV prevalence in Northern Uganda decreased from 26.0% in 1993 to 11.3% in 2001 (Fabiani et al., 2007). A National HIV/AIDS Sero-Behavioural Survey commissioned by the MOH Uganda in 2004 found that the total prevalence of HIV/AIDS for North Central Uganda was 8.2% (9% for women and 7.1% for men) (Ministry of Health Uganda & ORC Macro, 2006). This was in contrast to a national average of 6.4% and was significantly higher than the HIV prevalence in other largely rural areas such as the West Nile (2.3%); however it was lower than that in Kampala (11.8%). North Central Uganda is a region of civil conflict and is predominantly rural. The North Central districts include those in the Acholi region (Gulu, Lamwo, Amuru, Nwoya, Pader, Agago and Kitgum) and Lango region (Lira, Apac, Dokolo, Oyam and Amolatar). In 2005 an unlinked and anonymous HIV-1 surveillance at the antenatal clinics of St. Mary's Hospital Lacor (Lacor Hospital) in Gulu, St. Joseph's Hospital in Kitgum and Dr Ambrosoli Memorial Hospital in

Pader, found that the prevalence was not homogenous across the Acholi sub-region. The age-standardised HIV-1 sero-prevalence rate was 10.3%, 9.1% and 4.3% in Gulu, Kitgum and Pader respectively (Fabiani, et al., 2007). Gulu and Kitgum towns are semi-urban, while Pader is rural and geographically isolated.

The Uganda AIDS Commission (2007) postulated that the high HIV prevalence in North Central Uganda may have resulted from the 20-year civil conflict. No comparative studies have been carried out to explain the difference in HIV prevalence between Northern Uganda and other regions. Anecdotal evidence shows that the social and economic vulnerability of the population may have led to transactional sex occurring between military combatants and the general population; however this has not been confirmed by empirical studies. The former were seen as more affluent than the IDP population but unfortunately they were also at a higher risk of acquiring HIV (Uganda AIDS Commission, 2007). Rape, abductions and sexual and domestic violence could have also contributed to higher transmission; but again, this has not been ascertained (Uganda AIDS Commission, 2007). Accordingly, the social drivers of poverty, gender inequality, and human rights violations as identified by UNAIDS (2007b) may have made the population more vulnerable to HIV transmission.

Although Northern Uganda was identified as having a higher HIV prevalence, this was not immediately accompanied by an allocation of resources to combat the spread of the infection. Chronic lack of HIV prevention and curative services in the region during the conflict meant that people at risk of infection could not access the services they needed. For almost ten years from 1992, Lacor Hospital was the only facility providing VCT services, and the only antenatal sentinel surveillance site for Northern Uganda. PMTCT services started in 2001 and HAART only became available in 2004. Fortunately a reduction in hostilities, especially in the last five years, has resulted in an improvement in access to health services. Since 2004 there has been an increase in HAART provision through the MOH Global Fund Program and PEPFAR-supported HIV programs in this region (Wilhelm-Solomon, 2010). Efforts made by international, national and local agencies have led to a significant increase in the number of PLHIV on HAART from 1,228 people in 2004 to 9,994 people by the end of 2007. In addition, the number of health facilities providing

HAART in Northern Uganda increased from 5 to 35 during this period (World Health Organization, UNAIDS, & United Nations Children's Fund, 2008), making it easier for the population to access essential HIV services and HAART.

2.5 Summary of the Chapter

This chapter has provided an overview of the global HIV epidemic, the epidemic in Sub-Saharan Africa, as well as the current HIV situation in Uganda and Northern Uganda. The HIV epidemic continues to be a major public health problem which destroys the social and economic fabric of a society. Global and concerted efforts are still needed to control the spread of the disease. This chapter has also provided a summary of the risk factors for spread of the infection, and the contextual factors that drive the spread of the epidemic, especially in Uganda. It is essential that the local and regional epidemics are well monitored in order to implement appropriate, relevant and timely interventions to control the infection. The next chapter reviews the literature on factors that impact on the desire to have children among people living with HIV.

CHAPTER 3: LITERATURE REVIEW OF FERTILITY DESIRES AND INTENTIONS OF PLHIV

3.0 Introduction to the Chapter

The purpose of this review was to explore the literature around the factors associated with the desire to have children among PLHIV. The literature was examined within the Social Ecological framework (McLeroy, Bibeau, Steckler, & Glanz, 1988; Stokols, 1996) explicating the factors impacting on the desire to have children at the individual, interpersonal, community and structural levels. Included in this chapter is a peer-reviewed systematic review paper entitled "Nattabi, B., Li, J., Thompson, S. C., Orach, C. G., & Earnest, J. (2009). A Systematic Review of Factors Influencing Fertility Desires and Intentions Among People Living with HIV/AIDS: Implications for Policy and Service Delivery. *AIDS and Behavior, 13*(5), 949-968". This article examined the earlier literature (published between 1990 and 2008) on the factors associated with increased or decreased desire and intent to have children among PLHIV. The article is a more succinct version of this chapter but also critiqued the theories and frameworks in other studies around the desire to have children among PLHIV. At the end of this chapter, some conclusions are drawn and a summary of the chapter is provided.

3.1 Factors influencing the desire to have children among PLHIV

Several study designs and theoretical frameworks have been used to examine the desire to have children among PLHIV. Nattabi et al. (2009) provided a summary of the several ethnographies, cross-sectional, mixed-methods and generic studies conducted to explore and explain fertility desires among PLHIV. The Social Ecological framework (McLeroy, et al., 1988; Stokols, 1996) as described in detail in Chapter 4, provides a useful framework through which to examine the factors associated with, and those that influence, the desire to have children among PLHIV. No other study in the literature has used this approach, which acknowledges that the desire to have children among PLHIV is influenced by a multitude of factors and extends the focus to include the social environments with in which PLHIV desire to

have more children. In the next section, the factors in the literature that influenced the desire to have children among PLHIV at the individual, interpersonal, community and structural levels will be examined in detail. This next section expounds on the earlier literature review and includes articles published since 2008.

3.1.1 Individual level factors influencing desire to have children among PLHIV

In the literature, there were personal historical and biological factors that influenced the desire to have children among both male and female PLHIV. These individual-level factors included age, sex, relationship status, number of children, prospective motherhood and fatherhood, subjective health, experience of death of a child due to HIV/AIDS, concerns about orphanhood for the children, ethnicity, health-related concerns and feelings of internal stigma.

Age

In several studies, younger age was significantly associated with the desire to have children among PLHIV. Across a range of countries including Brazil (Nóbrega, et al., 2007; Santos, et al., 1998), Uganda (Nakayiwa, et al., 2006), South Africa (Myer, Morroni, & Rebe, 2007; Peltzer, et al., 2008), Canada (Loutfy, et al., 2009; Ogilvie et al., 2007) and the United States (Bedimo-Rung, et al., 2005; Chen, et al., 2001; Stanwood, Cohn, Heiser, & Pugliese, 2007), older PLHIV were less likely to desire more children with adjusted odds ratios (AOR) ranging from as low as 0.3 (95% CI: 0.1-0.6; $p < .01$) in Canada, to 0.94 (95% CI: 0.88–0.99; $p < .05$) in South Africa. Younger female PLHIV in Mbarara, Uganda were also three times more likely to desire to have children than those who were older (AOR= 3.03; 95% CI: 1.79-5.26); $p<.01$) (Maier, et al., 2009). Only one study did not find an association between age and the desire for more children (Sowell, et al., 2002).

The relationship between age and the desire to have children among PLHIV may relate to the fact that younger people have not yet had the chance to have their own families. In addition, they may have been more recently infected and thus not had severe manifestations of the disease. As will be discussed later, having fewer children and being healthier, characteristic of younger PLHIV, were also factors significantly associated with the desire to have children among PLHIV.

Sex

Though most studies have focused on HIV-infected women's desires and intentions, a few have found that HIV-infected men also continue to desire to have children after they have learned about their HIV-positive status (Chen, et al., 2001; Paiva, Filipe, Santos, Lima, & Segurado, 2003; Sherr & Barry, 2004). In fact the studies that have compared men and women have found that proportionally more HIV-infected men than HIV-infected women continue to desire children after they have learned about their HIV-positive status. Being male was associated with increased fertility desire in South Africa (AOR=2.58; 95%CI: 1.29-5.08) (Myer, Morroni, et al., 2007) and Brazil (Paiva, et al., 2003; Santos, et al., 1998). In Eastern Uganda, female PLHIV were less likely than male PLHIV to desire more children (AOR=0.12; 95% CI: 0.08–0.20): that is, men were over eight times more likely to desire to have children than women (Nakayiwa, et al., 2006). Of the 1,092 HIV-infected individuals studied, 174 (16%) wanted more children and of these individuals, 75% were men and 25% women.

Significant differences between both HIV-infected and non-infected males and females have also been found in Western Uganda, where women were 2.42 times (95% CI: 1.11-5.28; p=.027) more likely to want to stop childbearing in comparison to men (Heys, et al., 2009). In Homsy's (2009) longitudinal study of female PLHIV in rural Eastern Uganda, the desire to have children among female participants was consistently lower than that reported of their partners. Over a 24-month period, the level of their desire to have children remained persistently below 7%, ranging from 3.2% to 6.7%, while their partners' desire for children ranged from 15.9% to 25% over this same period. Of note is the fact that lack of desire did not translate into increased contraception use in these HIV-infected women. This was reflected in the low use of contraception and the higher-than-expected incidence of pregnancies in this population.

Though these aforementioned studies were carried out in different countries and were based on different sample sizes, a common finding was that men tended to be more likely than women to continue to desire for children after a HIV-positive diagnosis. This difference could be due to many factors, but could include the importance of

family continuity for the men, which will be discussed later in this thesis. Women infected with HIV have been found to be more worried about the effect of pregnancy on their health, especially possible deterioration, and concerns about the future of the orphaned children and potential infection of their children with the HIV virus. It is important to understand the desires of HIV-infected men and spouses of HIV-infected women, because in Sub-Saharan Africa husbands are often the chief profertility decision makers (Ezeh, 1993). As will be discussed in several chapters of this thesis, the high level of desire to have children among male PLHIV has a marked impact on their spouses' desires and intent to have children, and their use of contraception.

Relationship status

Not many studies have explored the relationship between marital status and the desire for children. Being married was significantly associated with the desire to have children among female PLHIV in Mbarara, Uganda, with married participants almost twice as likely to desire to have children than those who were not married (AOR= 1.94; 95% CI: 1.06-3.53). In contrast, being widowed was associated with a decreased desire to have children in this population (AOR= 0.24; 95 CI% 0.08-0.75; p<.05) (Maier, et al., 2009).

Number of living children

In seven cross-sectional studies, the number of living children was significantly associated with the desire for more children among PLHIV. PLHIV with at least one child were less likely to desire more children than those without children in South Africa (AOR=0.32; 95%CI: 0.15–0.69) (Myer, Morroni, et al., 2007), in Eastern Uganda (AOR=0.82; 95%CI: 0.75–0.90) (Nakayiwa, et al., 2006), Brazil (AOR=0.26; 95%CI: 0.09-0.69) (Nóbrega, et al., 2007) and the United States (among men p = .0804 and among women p = .0020) (Chen, et al., 2001). Another study in Kabarole, Uganda found that both male and female respondents with two or more children (79%) were more likely to want to stop having more children than those with one child or no children (25%) (p<.001) (Heys, et al., 2009). In Mbarara, Uganda, an increased number of live births was associated with a decreased desire to have children among HIV-infected females (AOR=0.35; 95% CI: 0.16-0.74; p<.01) (Maier, et al., 2009). In Canada, HIV-infected women with one or no children were

more likely to desire more than those women with two or more children (AOR=1.87;95% CI: 1.11-3.16; p=.02) (Loutfy, et al., 2009). In the USA, 40% of those who desired children had no children (Chen, et al., 2001), and in the UK, men who had children prior to an HIV diagnosis were more open to fostering and adopting children than those who had not had any children (Sherr & Barry, 2004).

A qualitative study in Cote d'Ivoire found that those with more than three children did not desire more in comparison to those with three or less. Unless a woman already had many children, it was difficult for her to explain to her family and society why she did not want more (Aka-Dago-Akribi, Du Loû, Msellati, Dossou, & Welffens-Ekra, 1999). In contrast, a South African study found no significant association between the number of living children and the desire for more children (Peltzer, et al., 2008). Although HIV-infected women were significantly less likely to desire more children (39%) than the HIV negative women (53%) (p = .002), there was a negative association between the desire for children and the number of existing children only among HIV-negative women (OR=0.83; 95% CI: 0.70–0.98) (Peltzer, et al., 2008).

Prospective parenthood: motherhood and fatherhood

The prospect of being a parent also had an impact on PLHIV's desire to have children in the future. An ethnographic study that examined the marriage and fertility desires of PLHIV in Nigeria showed the importance of marriage and parenthood in their life aspirations, regardless of their HIV status (Smith & Mbakwem, 2007). In the United States, the potential for motherhood was shown to be more influential for reproductive decision-making than health risks to mother and child (Siegel & Schrimshaw, 2001). In Hanoi, Vietnam, HIV-infected women were enthused about having their own children and were further encouraged by those who had given birth to HIV-negative children (Oosterhoff et al., 2008). According to PLHIV, having children made them look forward to the future and provided them with a reason for living (Cooper, et al., 2007; Kanniappan, Jeyapaul, & Kalyanwala, 2008; Sherr & Barry, 2004), allowing them to "feel complete and happy" (Siegel & Schrimshaw, 2001; Wesley, et al., 2000). Motherhood also meets important cultural and societal obligations, particularly in Sub-Saharan Africa, the importance of which should not be underestimated, due to the severe ramifications for women who cannot meet their

obligations in this regard (Hollos & Larsen, 2008). As will be discussed later in this Chapter, infertile women in Sub-Saharan Africa suffer domestic violence, ostracism from husbands and in-laws, and even divorce, because of their inability to have children.

Subjective health

Subjective health also has an impact on the desire for children among PLHIV. In the United States, HIV-infected women who felt healthier were more positive about having more children (Chen, et al., 2001), while in Nigeria and Switzerland, once PLHIV had commenced HAART, they were more likely to contemplate having children (Panozzo, Battegay, Friedl, & Vernazza, 2003; Smith & Mbakwem, 2007). In India, women on HAART noted an improvement in their health and felt more confident about having children in the future. However, they also felt that an improvement in their husbands' health was important, as this would ensure they would have support in nurturing the child (Kanniappan, et al., 2008).

Experience with child mortality due to HIV/AIDS

The experience of a child dying from HIV/AIDS had both a positive and negative influence on future desire for children among PLHIV. One study found that PLHIV felt that they should replace children who had died of HIV (Nakayiwa, et al., 2006). However in other studies, mothers who had experienced the death of a child due to AIDS were reluctant to have any more in case they too were infected. Some mothers even sought abortions to avoid similar experiences (Kanniappan, et al., 2008). One woman who had previously experienced a child death due to AIDS indicated that she could not go through a similar experience, saying "*I done lost one like that…I can't go through that no more.*" (Sowell & Misener, 1997); while in another study, a man was quoted as saying "*...feels like you have condemned an innocent soul…*" (Cooper, et al., 2007). In contrast, a quantitative study in Brazil reported that the death of a child from AIDS did not seem to have any effect on the desire for a child (Nóbrega, et al., 2007) although reasons for this were not explored.

Orphanhood

HIV-infected mothers were concerned not only about their children's deaths, but their own deaths as well. In particular, they were worried that if they died soon, there

would be no one to take care of their children (Kanniappan, et al., 2008; Sowell & Misener, 1997; Sowell, Phillips, & Misener, 1999). Many women desired to look after their own children and worried that other people, including family members, might not look after their children adequately (Richter, et al., 2002). Some were concerned about leaving behind HIV-infected orphans who would be particularly vulnerable, while other women in the same study were more hopeful and did not let these concerns prevent them from considering having children (Richter, et al., 2002).

Stigma related issues: Internal stigma/negative self perception

In Cote d'Ivoire and South Africa, HIV-infected women reported that in order to avoid stigmatisation by the community, they continued to have children in order to conceal their serostatus (Aka-Dago-Akribi, et al., 1999; Cooper, et al., 2007). A study of PLHIV in the United States found that stigma affected fertility desires in both directions (Craft, et al., 2007). In a study that used the HIV stigma scale developed by Berger et al. (2001), stigma seemed to enhance the probability of getting pregnant in those women with apparently higher levels of personalised stigma and negative self-image, while it seemed to reduce the probability of getting pregnant in those with higher levels of disclosure and public attitudes stigma (Craft, et al., 2007).

Personalised stigma relates to personal experiences of stigmatisation or fears of rejection, while negative self-image refers to the negative feelings towards oneself because of having HIV (Berger, et al., 2001). For women with higher levels of personalised stigma and negative self-image, having more children would help conceal their infected status, thus avoiding stigmatisation while at the same time improving their feelings of self worth (Craft, et al., 2007). Disclosure relates to PLHIV keeping their status secret and controlling who knows their status. Public attitudes stigma refers to concerns about communities' attitudes towards people with HIV (Berger, et al., 2001). Thus some PLHIV were less likely to become pregnant or desire more children in order to avoid society's criticism of seemingly inexcusable behaviour: that of having a child when infected with HIV and knowing the risks of transmission (Craft, et al., 2007).

Health-related concerns

In several studies, HIV-infected women were mainly concerned about infecting their partners and future children, together with the effects of future pregnancies on their own health (Baek & Rutenberg, 2005; Cooper, et al., 2007; Craft, et al., 2007; Kanniappan, et al., 2008; Oosterhoff, et al., 2008; Richter, et al., 2002; Siegel & Schrimshaw, 2001; Wesley, et al., 2000). Some HIV-infected men had similar concerns (Paiva, et al., 2003). Many women were worried that additional pregnancies would result in their health deteriorating faster and felt that instead of having more, they should take care of their existing children (Baek & Rutenberg, 2005; Kanniappan, et al., 2008). Some mothers felt that the potential trauma of their child being infected with HIV would be too much for them to bear, while others were not convinced of the effectiveness of the PMTCT regimen (Kanniappan, et al., 2008). Others expressed feelings of guilt for giving birth to an infected child (Aka-Dago-Akribi, et al., 1999). However, other studies found that some women continued to have considerable interest in having more children even after considering the risks to themselves, their partner and potential children (Aka-Dago-Akribi, et al., 1999; Siegel & Schrimshaw, 2001).

Ethnicity

Ethnicity was found to be associated with the intent, but not the desire, to have children in a US study population that was 51% black, 31% white and 15% Latino. Among the black population, PLHIV intended to have children but did not particularly desire to have them (Chen, et al., 2001). Similarly, a Canadian study also reported that African ancestry was significantly associated with the desire and intent to have children among 490 HIV-positive women living in Ontario, Canada (Loutfy, et al., 2009). In this study, women of African ancestry were three times, ten times and almost 4 times more likely to intend to have children than women of Caribbean, European-British/French-Canadian and Aboriginal ancestry, respectively. Ethnicity was not found to be associated with the desire for more children among a group of women in New York (Stanwood, et al., 2007) nor with becoming pregnant or continuing a pregnancy after being diagnosed with HIV in New Jersey (Kline, Strickler, & Kempf, 1995). Other studies that had several ethnic groups did not explore the association of ethnicity with the desire for children (Bedimo-Rung, et al., 2005; Siegel & Schrimshaw, 2001; Wesley, et al., 2000).

3.1.2 Interpersonal level factors influencing desire to have children among PLHIV

In the literature, the factors at an interpersonal level that impacted on the desire of PLHIV to have children included spousal and family demands, and health worker attitudes.

Spousal and family influences

Spousal and family expectations for childbearing also have an important influence on PLHIV reproductive desires and intentions. Husbands had a particularly strong influence on reproductive desires among some HIV-infected women in the US: having a child was viewed by these women as a means of strengthening their relationship with their husband or partner (Siegel & Schrimshaw, 2001; Sowell, et al., 1999). In India, a husband's support was crucial, and the decision on whether or not to have a child was made jointly with the husband (Kanniappan, et al., 2008).

In regards to family influences, in South Africa, HIV-infected men were not under as much pressure from the family and the community to have children as women were (Cooper, et al., 2007). In Vietnam, both men and women were particularly pressured by older female family members to have children (Oosterhoff, et al., 2008). PLHIV in Vietnamese society do not make fertility decisions on their own and they feel a lot of stress because they not only have to consider the potential risks to themselves and future children, but they also have to meet their families' demands. In Taiwan, pregnancy and childbirth are seen as not only fulfilling expectations of lineage preservation, but also a means of enhancing the relationship between a woman, her husband and his family. Despite misgivings about having children, HIV-infected women ultimately had to obey their husbands (Ko & Muecke, 2005).

Family members' positive attitudes to child-bearing also encouraged PLHIV to consider having children (Wesley, et al., 2000). Some HIV-infected women received support and promises from family members to look after their children in the event of their death (Kanniappan, et al., 2008; Sowell, et al., 1999). However, not all fertility decisions were influenced by spouses, family and society (Craft, et al., 2007). Focus group attendees from the states of Georgia and South Carolina in southern USA indicated that many of them were single, were not in any permanent

relationship and that the decision to have children was theirs alone (Sowell & Misener, 1997). These were mainly African-American women who reported that their sexual partners did not necessarily have the right to influence their reproductive decision-making process.

Health worker attitudes

It is important to understand the role that health workers play in respect of the desire to have children among PLHIV. This is because their support, or lack thereof, can impact on PLHIV's desire or intent to have children, or at the very least impact on their access to care. As chronically ill people, PLHIV consistently come in contact with health workers either during acute episodes of their illness or during long-term management of their infection through PMTCT and HAART programs. Therefore health workers are one of the most important influences on PLHIV. A study of HIV-infected women in South Africa reported they felt that health workers did not approve of their reproductive behaviour post-HIV diagnosis, and generally discouraged discussions about fertility issues (Cooper, et al., 2007). Only 5% of PLHIV in Brazil felt that they could discuss their reproductive desires with their doctor and receive support for their reproductive decisions (Nóbrega, et al., 2007).

In the United States, women with HIV said they preferred to obtain relevant information from other HIV-infected women. This was because they felt health workers did not provide adequate information for them to make informed reproductive decisions, but rather provided biased information in order to discourage them from having more children (Sowell & Misener, 1997). Though health workers seemed to encourage their clients to consult with them when they wanted to discuss future reproduction, the clients in South Africa felt that the health workers would discourage them from trying to reproduce in an effort to prevent orphans (Nduna & Farlane, 2009). Discouraging behaviour by health workers was not reported in Vietnam, where they were more supportive and did not question their patients' desires to have children due to an understanding of the cultural implications of not having children in their society (Oosterhoff, et al., 2008). In a study conducted in Ohio, USA, health workers' attitudes, positive or negative, reportedly did not influence PLHIV women's fertility decisions (Craft, et al., 2007).

3.1.3 Community level factors influencing desire to have children among PLHIV

Community level factors that impacted on the desire of PLHIV to have children included community disapproval, and cultural norms and expectations.

Community disapproval and stigma-related concerns

Some PLHIV were concerned about having children because of perceived stigma towards themselves and their children (Oosterhoff, et al., 2008; Santos, et al., 1998). In Britain, heterosexual HIV-infected men felt that they would face discrimination from the community if they continued to have children (Sherr & Barry, 2004), while in Zimbabwe, 64% of PLHIV felt that their community and relatives would disapprove of PLHIV having more children (Feldman & Maposhere, 2003). In South Africa, it was considered socially unacceptable for PLHIV who had publicly disclosed their HIV status to have more children (Cooper, et al., 2007).

Cultural norms and expectations

Several studies have examined the impact of culture on the fertility desires of PLHIV. These included Ko and Muecke's (2005) ethnographic study in Taiwan, Smith and Mbakwem's (2007) study in Nigeria, Aka-Dago-Akribi et al (1999) study in Cote d'Ivoire and Oosterhoff et al (2008) study in Vietnam, all of which showed the strong influence of culture on the desire to have children. According to Sonko's (1994) review of fertility and culture in Sub-Saharan Africa, it is important to include cultural factors in explaining fertility behaviour of a people. Sonko (1994) defined culture as "the sum total of a people's belief systems, practices, values, norms, perceptions, morals and customs". Culture was at the centre of Airhihenbuwa's PEN-3 model, which highlighted the factors that influenced individual, family and community health actions, including perceptions, enablers and nurturers (Airhihenbuwa, 1995). Perceptions comprised the knowledge, attitudes, values and beliefs, within a cultural context, that may facilitate or hinder personal, family and community motivation to change behaviour. Enablers were those cultural, societal, systematic or structural influences or forces that may enhance or inhibit change, such as the availability of services in health facilities. Nurturers were those external factors that influenced health beliefs and attitudes and that motivated health

behaviour and actions: e.g. extended family, kinship, peers and the community (Airhihenbuwa, 1995).

In Sub-Saharan African cultures, early marriages, bridewealth and arranged marriages, polygyny, a strong emphasis on the preservation of the lineage, preference for male children as well as the low status of women and reliance on human labour for agricultural activities, all put pressure on individuals and societies to produce as many children as possible (Sonko, 1994). These same factors ultimately determine the value of children. Exchange of women for bridewealth in many African societies takes the reproductive decisions out of a woman's hands and into those of her husband and his family. This means that the husband and his family have the rights to the children, and are entitled to receive the bridewealth back if the woman does not 'produce the goods' for which she was paid (Hollos & Larsen, 2008). Women in such situations are at risk of being divorced, shunned, stigmatised and harassed; at the very least, their husbands take on other wives who can meet these requirements. Polygyny makes women compete with each other to have as many children as possible to improve their status level and respect from other family members and the society (Sonko, 1994). Low education levels of women and strong patrilineal systems in Africa and Asia further disable women to make decisions about their reproductive lives. Therefore for many poor, uneducated African women, their livelihood is tied to their ability to have children.

However, it is not only poor uneducated women in Africa who have to fulfil their social obligations to kin and community. Hollos and Larsen (2008) examined the importance of motherhood in Sub-Saharan Africa, exploring it through the stories of infertile women from an urban town in Tanzania. They found a raft of social and personal ramifications that women, who could not have children, suffered as a result of their infertility. Their studied population was more urban and more educated than other studied populations and they expected to find lower social obligations for women in this type of environment, given the different social and economic context. Rural, poorer and less educated communities are expected to place more value on children because economic, cultural and social implications are high. In some societies in Africa, having children is a milestone that all people aspire to reach (Hollos & Larsen, 2008; Smith, 2001).

In many African societies, children have economic value, as they provide a wide range of services, including labour. As adults, they provide care and financial support, look after aged parents and help with educating their siblings (Hollos & Larsen, 2008). Inhorn and van Balen (2002) also found that children in Africa are important because they secure their parents' and family's survival; they support aging parents in a context of no formal support for the elderly through pensions, nursing homes etc; they serve as a valuable power source for their mothers, especially in polygamous families; they continue the group structure into the future and may also serve as political investment, especially in societies where there are strong ethnic and cultural liaisons. Hollos and Larsen (2008) found that even infertile women in more affluent communities also suffer if they are unable to have children. Though the kinship ties were not as strong in urban areas, and children were not expected to provide as much labour or support to parents as they would in a rural setting, women in urban Tanzania were also expected to have children and were under pressure from spouses and in-laws to have children. Community stigma towards infertile women, particularly from other women, was strong. Infertility was certainly not a choice: infertile women suffered insults, they were ostracised by their husbands and/or his family members; they had no respect from family or community members; they were threatened with divorce if married; or if they weren't fully married, bridewealth would not be paid in full (Hollos & Larsen, 2008). In fact they remained in cohabitation, and thus in an unstable marital state, and were only fully married when they were able to have children. Because parenthood in many African societies is the major purpose of, and primary value of, a marriage, an individual is not complete until they have had children of their own (Fortes, 1978; Smith, 2001).

Fortes (1978) argued that fertility "was and still is valued above all other human endowments, in all strata and among all types of African society…and its value primarily was the indispensible condition for the achievement of parenthood" (p. 125). He found that parenthood was about more than individual fulfillment; it was also a "fulfillment of fundamental kinship, religious and political obligations and represents a commitment by parents to transmit the cultural heritage of the community" (p. 125). Therefore, a child is not only born to its parents but also into a lineage, a clan and community, the survival of all of which depends on the birth of

children. In other words, though a child is born biologically to its parents, they are born into a network of kinship and descent groups and it is from these connections, therefore, that "each individual derives his/her place in society" (Fortes, p. 128).

Though Fortes', Hollos and Larsen's and Smith's studies were not conducted among PLHIV, they provide an insight into the context within which PLHIV in Africa have to make decisions around having children in the future. These studies explicate the social 'drivers' that put people living in Africa under immense social pressure to have more children, regardless of their individual circumstances. As Inhorn and van Balen put it: "not having children is seldom viewed as a choice or lifestyle option" (2002, p. 9), this holding true regardless of education or attainments in other spheres of life (Hollos & Larsen, 2008).

Confucian doctrine which prevails in some countries in Asia such as Taiwan and Vietnam emphasises preservation of the family lineage, and thus influences fertility decisions (Ko & Muecke, 2005; Oosterhoff, et al., 2008). Cultural factors such as social desirability of having children also have influence; in Vietnam for example, cultural influences on child-bearing have influenced the policy change towards child-bearing among PLHIV (Oosterhoff, et al., 2008). Poor women of colour in the United States also consider having children to be important: a woman's fertility, motherhood and family are of great value among Black and Latino communities especially in poorer neighbourhoods (Levine & Dubler, 1990). Women without children in some societies in Africa and Asia are considered incomplete and are ridiculed, stigmatised and isolated. Infertility has severe consequences for these women, including marital instability and domestic violence (Caldwell & Caldwell, 1987; Cooper, et al., 2007; Dyer, Abrahams, Hoffman, & van der Spuy, 2002; Oosterhoff, et al., 2008).

Infertile men in some African societies also face ridicule and stigmatisation. Men attending a fertility clinic in South Africa reported that they routinely faced verbal abuse from community members with comments such as 'failure', 'shooting blanks', 'you are a woman' and they described feelings of anger, frustration and worthlessness (Dyer, Abrahams, Mokoena, & van der Spuy, 2004). Thus having children is an imperative for both male and female identity in many cultures. PLHIV

may rather face the consequences of HIV transmission to their partners and children than be labelled 'infertile'. Ko and Muecke (2005) called it 'cultural competence', where health workers recognise and appreciate the significance of specific cultural values of PLHIV that shape their fertility decision making.

3.1.4 Structural level factors influencing desire to have children among PLHIV

In the literature, structural level factors that had an impact on the desire and intent to have children included policies that were developed or implemented that impacted on the access to health services such as PMTCT and HAART programs.

PMTCT and HAART programs

Several studies have found that PMTCT programs and HAART programs have a positive impact on reproductive decision-making (Cooper, et al., 2007; Kanniappan, et al., 2008; Peltzer, et al., 2008; Smith & Mbakwem, 2007; Williams et al., 2003). Overall, PLHIV were more likely to desire to have children when informed about and/or when able to access PMTCT and HAART programs. When educated about the positive effects of PMTCT on infant health, men in South Africa were more inclined to have children than women, regardless of availability of HAART, whereas among women, PMTCT in combination with HAART availability influenced their future reproductive intentions (Cooper, et al., 2007). Couples in Vietnam felt that access to HAART would improve their health and enable them to be healthier parents (Oosterhoff, et al., 2008). For women in India, access to both PMTCT and HAART was a major consideration in making a decision on whether or not to have a child (Kanniappan, et al., 2008). The Indian women who believed in the efficacy of PMTCT and were able to access both PMTCT and HAART were more likely to have children than those who didn't. PLHIV in Nigeria reported that improvements in their health status after initiating HAART had allowed them to reassess their life goals and possibilities for marriage and childbearing and hence increased their desire and intent to have children in the future (Smith & Mbakwem, 2007).

In South Africa, HIV-infected women who had been on HAART for more than 12 months were more likely to desire children in comparison to those would had been on HAART for less than a year (adjusted odds ratio (AOR) = 3.52; 95% CI: 1.44 –

8.60) (Myer, Morroni, et al., 2007). In Mbarara District, Uganda, a study that compared female participants on HAART and other female participants not on HAART, HAART use was significantly associated with desire to have children (AOR=2.99; 95% CI: 1.38-6.28; p<.01) (Maier, et al., 2009). Another Mbarara study found that women who strongly believed in the efficacy of HAART and thought it would reduce rate of infection to partners and children by making PLHIV less infectious were significantly more likely to desire to have more children than those who did not (Kaida et al., 2009). Only one study showed that not currently being on HAART was positively associated with desire for children among women (AOR=9.63; 95% CI: 1.92 – 48.39) (Stanwood, et al., 2007). This probably reflected the less advanced stage of their disease in comparison to those on HAART and thus its effect on their desire for children. Similarly, it was only in one study in Uganda where knowledge of PMTCT did not have significant relationship with desire for children (Nakayiwa, et al., 2006).

Next, the first peer-reviewed article in this thesis is presented. Though the content is very similar to the content of this chapter, it also includes a table on the various studies conducted worldwide on the desire to have children among PLHIV, together with a critique of the theoretical frameworks and methodological approaches of these studies.

3.2 Article 1: A Systematic Review of Factors Influencing Fertility Desires and Intentions Among People Living with HIV/AIDS: Implications for Policy and Service Delivery.

Published: AIDS and Behavior

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3.3 Conclusion

From the review of the literature concerning fertility desires among PLHIV, it is evident that the desire to have children among PLHIV is influenced by a myriad of individual demographic, health-related, stigma-associated, psychosocial, and cultural factors. Some PLHIV desire to have more children, while other PLHIV do not want to have any more. The desire to have children within the same individual can also vary over time. Furthermore, a lack of desire to have children does not automatically translate into the use of contraception to prevent future pregnancies; in fact, a significant number of PLHIV who do not want to have more children continue to have children. Although this review has indicated the factors most significantly associated with the desire to have children, it is clear that older age, already having children, not being in a stable relationship or a painful loss of a child to HIV does not necessarily lessen the desire to have more children among PLHIV (Nduna & Farlane, 2009).

Using the Social Ecological Framework, the influences on the desire to have children at the individual, interpersonal, community and structural level were examined in detail. The individual factors included age, sex, relationship status, number of children, prospective motherhood and fatherhood, subjective health, experience of death of a child due to HIV/AIDS, concerns about orphanhood for the children, ethnicity, health-related concerns and feelings of internal stigma. The interpersonal factors included spousal and family influences, as well as interactions with health workers. Community level factors included community disapproval and expressions of stigma towards PLHIV, as well as cultural norms and expectations. Structural level influences included the availability and access to PMTCT and HAART programs to PLHIV. Later in Chapters 5, 6 and 7, where the data from this research study is presented, it will be apparent that many of these factors impact on the desire to have children in Northern Uganda, some more so than others.

3.4 Summary of the Chapter

This chapter has reviewed the major factors that impact on the desire to have children among PLHIV. The next chapter describes the research methodology and

study design, and discusses in detail the study's rationale, research aims, objectives, significance, paradigm and conceptual framework.

CHAPTER 4: RESEARCH DESIGN AND METHODS

4.0 Introduction to the Chapter

This chapter describes the research methodology and study design. The chapter commences with a discussion of the rationale, research aims, objectives, significance, paradigm and conceptual framework of the study. It is then divided into two sub-sections describing the qualitative and quantitative arms of the study. The first section, covering the quantitative arm of the study, describes the quantitative sampling procedures, the survey questionnaire used and quantitative data analysis. The next section, detailing the qualitative arm of the study, describes the qualitative study sample, sampling procedures, and the approach to the qualitative data analysis.

4.1 Rationale for studying fertility desires and intentions among PLHIV

As a medical doctor, public health physician and head of St. Mary's Hospital Lacor's HIV clinic for more than four years, I had observed that there were a number of HIV-infected clients attending the clinic who were becoming pregnant. Quite a number of clinic attendees, particularly those clients on HAART, had approached the clinic doctors asking whether they could commence having children. On one occasion, the nurses brought a female client to me who had commenced on HAART about one year before. I estimated her to be about eight months pregnant. When I asked her if she was pregnant, she replied in an irritated tone, "You tell me". She obviously felt it was not my concern.

Pregnancies among PLHIV have sometimes been problematised, especially among those who are known to be HIV-infected (Cooper, et al., 2007). During counselling sessions with our HIV-infected clients, we always emphasised the possible transmission risks to unborn children and potential sexual partners, on the assumption that the PLHIV would adhere to our advice to avoid having children and unprotected sex. Therefore we were puzzled and did not particularly know how to handle this new 'problem'. We wanted to get on with treating the clients and not

have to worry about resultant children and their risk of acquiring HIV. When I enrolled for my PhD, I decided to explore this issue in detail. I was interested in finding out how many clients were interested in having children, and why; and I was particularly interested in what this meant for our future practice and delivery of health services to PLHIV.

As examined in the literature in Chapter 3, many PLHIV continue to have children despite HIV transmission risks to their partners and unborn children. A plethora of studies, both quantitative and qualitative, have examined this phenomenon in order to understand the factors that influence fertility desires among PLHIV and found that their desires are influenced by several demographic, health, psychosocial, and cultural factors (see Nattabi, et al., 2009 for details). Several demographic factors such as younger age, being male, and having fewer children have been found to have a significant association with an increased desire to have children. Whilst HIV-related stigma in particular was also an important factor in determining whether PLHIV decided to have children, it had a complex relationship with the desire to have children among PLHIV. Some PLHIV preferred to have children in order to hide their HIV status and protect their reputations (Smith & Mbakwem, 2010) while others avoided having children altogether for fear of being condemned (Craft, et al., 2007). Equally important was the effect of spousal, family and societal expectations of individuals to have children especially in strongly patriarchal societies. In societies where marriage and having children were an important part of social and family obligations, PLHIV desired to have children in order to fulfil their own social obligations. Whilst not disregarding their health and that of their partners and children, the relevant social and cultural obligations sometimes overrode their public health and personal health concerns (Smith & Mbakwem, 2010).

It was therefore apparent from the literature that there are several influences on the desire to have children among PLHIV. However, for many of the studies the context in which PLHIV made these decisions was not always elucidated. The desire of HIV-infected persons to have children in Northern Uganda has significant implications for the transmission of HIV to sexual partners and newborns, because access to PMTCT and HAART interventions is not universal. The region also has a high HIV prevalence and has lagged behind other regions in Uganda in HIV prevention and

treatment programs. The risk of HIV transmission to HIV-negative partners is likely to increase as more HIV-infected individuals choose to have children. Many children of HIV-infected parents are likely to need considerable care, treatment and social support. Thus a holistic description of the fertility desires and intentions of PLHIV in Northern Uganda was needed in order to tailor counselling, care and treatment programs for HIV-infected persons. At the same time, understanding the context in which PLHIV made these decisions was important.

4.2 Research Aims and Objectives

The overarching aim of the study was to gain a better understanding of the fertility desires of HIV-infected men and women living in post-conflict Northern Uganda and the implications for HIV transmission, particularly MTCT of HIV and medical and public health practice.

4.3 Research Questions

The study sought to answer the aim through two major research questions:

1. What are the fertility desires and intentions of HIV-infected men and women in post-conflict Northern Uganda and what are the factors that influence their reproductive decision-making? What influences these decisions and choices?
2. Based on their desires and intentions, what are their needs as regards HIV prevention and care programs? What family planning services are available to HIV-infected women and men in Northern Uganda and how accessible are they?

The study had the following specific objectives:

1. To describe and explore the determinants of fertility desires and intentions of the HIV-infected women and men attending three HIV clinics in Gulu district;
2. To investigate access to family planning services among HIV-infected women and men attending three HIV clinics in Gulu district and to explore the structural/environmental, community and individual factors that enhance or restrict their ability to plan, space and limit their family sizes;

3. To examine the level of integration of family planning services with HIV/AIDS programs at health facility and national levels; and
4. To suggest an appropriate model for delivery of family planning services to the HIV-infected women and men attending these HIV clinics in Gulu district, with possible implications for HIV-infected populations in other regions in Uganda.

4.4 Research Paradigm

The study used a mixed-methods approach underpinned by a pragmatic paradigm. A paradigm is defined as a comprehensive belief system or framework that guides research and practice in a field and encompasses the application of the entire framework on research practice (Willis, 2007). Paradigms have "explicitly stated laws and theoretical assumptions, standard ways of applying the laws, instrumentation and instrumental techniques, general metaphysical principles that guide the work and general methodological prescriptions about how to conduct work within the paradigm" (Chalmers, 1982). As an overarching ideological stance, a paradigmatic positioning relates to a researcher's epistemological (understanding of the nature of knowledge) and ontological (nature of reality) stand-points (Broom & Willis, 2007).

Postpositivism

In postpositivism, the nature of reality is considered to be external to the human mind: an accessible, external and physical reality that can be 'discovered' by objective research methods. The purpose of postpositivist research is to find concepts or ideas that can be applied to different settings and generalised across contexts (Willis, 2007). Features of a positivist paradigm include determinism (phenomena can be predicted), objectivity (the researcher can maintain objectivity), quantification (information can be quantified), reliability (findings can support or negate a hypothesis) and generalisability (data is reliable and unbiased and can be generalised to the rest of the population) (Broom & Willis, 2007). Postpositivist researchers deny any subjectivity that may influence their conduct of research and claim that the selection of the research topic, the creation and use of the research instruments and the interpretation of the data are value-free (Willis, 2007).

Interpretivism

Interpretivists argue that realities exist in the form of multiple mental constructions that are socially and experientially based, and that they are local, specific and their form and content are dependent on those who hold them (Guba, 1990). To interpretivists, research is a socially constructed activity and only access to a socially constructed reality is possible (Willis, 2007). Features of the interpretivist paradigm are interpretivism (research seeks understanding with a focus on subjective meanings), naturalistic (data collected in the setting of everyday life), subjectivity (knowledge production is subjective), and complexity (research delves deep into participants lives with no intent to generalize findings) (Broom & Willis, 2007). Because these paradigms essentially hold foundationally differently assumptions, it is seen by some as impossible to merge methods in a single study. Broom and Willis (2007) argue that health research cannot be simultaneously quantitative and qualitative, that social reality cannot be both objectivist and subjective.

Pragmatism

Pragmatism, the over-arching philosophical foundation for this mixed-methods study, is a relatively new paradigm (Plano Clark, Huddleston-Casas, Churchill, Green, & Garrett, 2008; Teddlie & Tashakkori, 2009) and is seen as an alternative to other paradigms in social sciences research, that is, postpositivism, critical theory and interpretivism (Feilzer, 2010). Within the pragmatic framework, this study avoided the contentious debate of whether quantitative or qualitative research methods are irreversibly tied to particular epistemology and ontology, but rather saw the techniques of data collection or analysis as independent of paradigms. As with any research study, it was essential to answer the research question appropriately and the emphasis was on how best to answer the research question. In fact, pragmatists argue that the 'paradigm wars', i.e. the debate about which paradigm is appropriate for research, detract from important issues, such as what question needs to be asked and how best to answer it (Feilzer, 2010). Many mixed-methods researchers justify their work under a pragmatic paradigm, whilst others are 'a-paradigmatic', that is, they are not concerned with epistemological or philosophical issues and yet other mixed-methods researchers are 'multi-paradigmatic', i.e. they apply several paradigms to the same study (Teddlie & Tashakkori, 2009).

Some mixed-methods researchers justify their approach on pragmatic rather than ideological grounds, in order to study complex problems (O'Cathain, 2009). The pragmatic paradigm allows researchers to circumvent the contentious issues of 'truth and reality', and acknowledges that there are singular and multiple realities open to empirical inquiry. This paradigm orients itself towards solving practical problems and allows new and deeper dimensions to emerge (Feilzer, 2010). Pragmatism also provides a more reflexive approach to research design and implementation (Feilzer, 2010). Irrespective of the paradigm mixed-methods scholars chose to use, mixed-methods studies are not inherently superior to mono-method studies, need to be competently designed and conducted with rigor, and must be appropriate to answer the research questions (Tashakkori & Teddlie, 2003). Researchers who use mixed methods should use the data in an integrated manner in the analysis, interpretation and write up of findings (Teddlie & Tashakkori, 2009).

Bryman (2006) identified at least 16 reasons why researchers combine qualitative and quantitative methods which include triangulation, instrument development, credibility, and illustration. The objective of the mixed-methods approach in this study with separate and concurrent qualitative and quantitative data collection phases was to allow the methods to complement each other, to provide explanation and enhancement of findings from each arm of the study, and provide completeness to each other. The intention was to give equal strength to both arms of the study as the methods were designed to complement each other to better understand the processes of fertility decision-making among PLHIV. The sources of data, which are described in detail later, included structured interviews and semi-structured interviews with PLHIV and interviews with hospital and district officials and officials from relevant local, national and international organisations.

4.5 The Conceptual Framework

This study used as its conceptual framework the Social Ecological Framework (McLeroy, et al., 1988; Stokols, 1996), which proposes that the factors that influence an individual's behaviour are at a multitude of levels. McLaren and Hawe (2005) described this conceptual framework as one designed to illuminate individual and

environmental determinants of behaviour and the interaction between these levels. The ecological perspective encompasses all the physical, social, cultural environments as well as the individual attributes that impact on behaviour. The model assumes that changes to the social environment are necessary to effect changes in individual behaviour (McLeroy, et al., 1988). However, individual changes are also required to effect environmental changes. Improvement or change in behaviour thus requires that interventions are targeted at these different levels in order to be effective.

The 'ecological approach' to research and development of interventions historically has its roots in various disciplines, including sociology. This approach to public health and health promotion gained significance in the 1970s following an increasing acknowledgement of the complexity of public health problems and after a realisation that factors influencing health existed at various levels (McLaren & Hawe, 2005). An ecological approach allows an analysis of the context that includes the physical, social, cultural, and historical aspects of the environment as well as individual's attributes and behaviours and emphasizes study of human behaviour in natural contexts (McLaren & Hawe, 2005). Many individual-oriented behaviour models of health promotion that were developed seemed to 'blame' individuals for their ill-health or behaviour instead of focusing on the social and physical environments that maintained and reinforced unhealthy behaviour (McLeroy, et al., 1988).

The social ecological perspective has at least five different core principles as regards interactions between environments and individual behaviour (Stokols, 1996). The first core principle is that the environment has multiple physical, social and cultural dimensions that can influence a variety of outcomes e.g. health status and emotional wellbeing. The second core principle is that human health or behaviour is also impacted by a multitude of personal attributes e.g. sex, age, and education. Stokols (1996) also stated that there is mutual influence between the environment and individuals, with the environment impacting on individuals' health, and individuals also modifying their environment through their actions. Fourthly, there is an interdependence and interconnection between various levels of the physical, social and cultural environments, for instance, between an individual's residence, workplace, neighbourhood and surrounding community. The fifth core principle is

that the social ecological approach to research and practice is interdisciplinary in nature, combining individual-level approaches used in medicine with public health preventive strategies. This approach uses multiple levels of analysis and diverse methodologies to determine the health and behaviour of people and communities (Stokols, 1996).

In Figure 1 below, adapted from McLaren and Hawe (2005), the series of centric circles illustrate levels of influences on behaviour and the arrows between the levels illustrate interaction or the relationships between the levels and systems. The levels include:

- The microsystem which includes an individual's immediate environment e.g. peers, family and friends.
- The mesosystem refers to the overlap between the environments in which the individual participates e.g. church, community and workplace (McLaren & Hawe, 2005).
- The exosystem which includes other environments which may not be in an individual's immediate environment, but still have an impact on him/her e.g. mass media. Though these factors may not be in the immediate environment, they still have a major impact on an individual's behaviour.
- The macrosystem which is the overarching concept of the ecological environment of a person and includes the complete network of systems that may impact on an individual's behaviour i.e. the micro-, meso- and exosystems. The macrosystem may be used to describe the culture or organisation of a society (McLaren & Hawe, 2005).

The ecological framework, as used in this study, proposes that no single factor can explain why some PLHIV desire to have children in the future and others do not. This framework views the desire to have children as the outcome of the interaction of factors at four levels, that is, individual, interpersonal, community and structural levels. The social ecological framework is applied throughout this thesis, whether it is explaining the factors influencing the desire to have children, factors impacting on the access and use of family planning methods, or the experiences of stigma among PLHIV in this region. As the quantitative and qualitative results are presented in

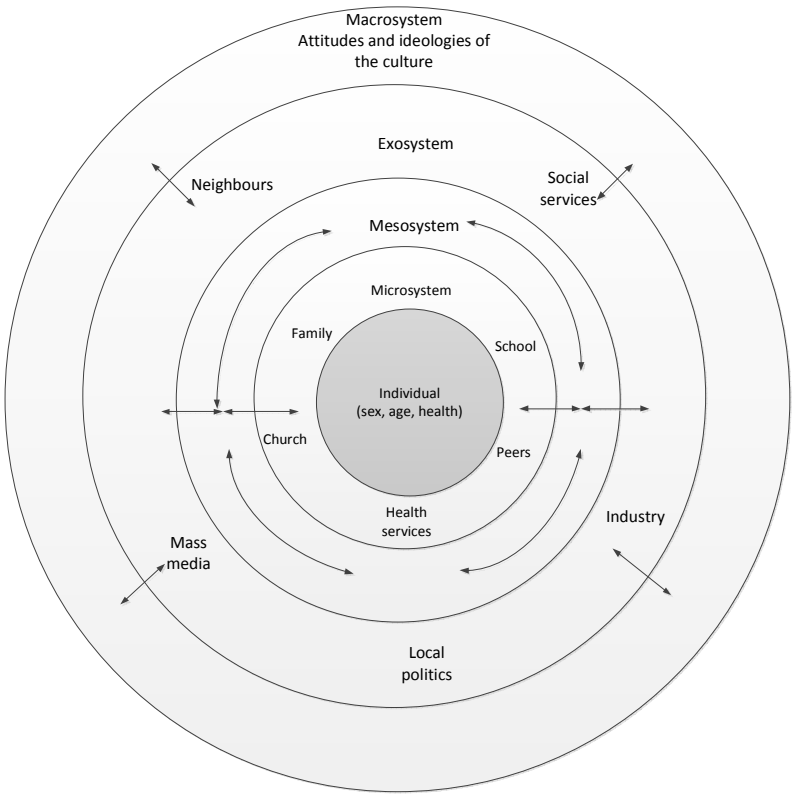

Figure 1: Brofenbrenner's ecological theory of development

Adapted from McLaren and Hawe (2005)

Chapters 5, 6 and 7, the factors at the individual, interpersonal, community and structural levels in Northern Uganda will be revealed.

4.6 Study Design

This was a cross-sectional study that used both qualitative and quantitative research methods. The quantitative methods were designed to collect information on the characteristics of individuals and determine associations between the key independent variables and dependent variables. The qualitative methods and data were designed to assist in gaining a deeper understanding of the desire to have children among PLHIV, the use of family planning methods and the contextual factors that either facilitated or hindered use of contraception, as well as a detailed understanding of the processes of stigmatisation of PLHIV in Northern Uganda. The methodological triangulation was an attempt to integrate qualitative and quantitative data, and their associated methods, with the different methods being used to capture different components of a multi-dimensional construct (Sim & Wright, 2000). Hence, using both qualitative and quantitative data to complement each other, this study

sought to derive theoretical insights from the concepts, themes and issues emerging from the research findings that were sufficiently generalisable so as to be applicable to other comparable situations (Sim & Wright, 2000), as well as statistical representativeness of the general population, respectively.

There was concurrent, but separate, collection and analysis of qualitative and quantitative data with equal emphasis on both arms of the study and the results of the two strands were converged. This type of mixed-methods design is referred to as a convergent design, notated as 'QUAN + QUAL = converge' (Creswell & Plano Clark, 2007). Using Teddlie and Tashakkori's (2009, p. 151) typology, this was a mixed-methods, multi-strand, parallel mixed designs study. In each strand there were three stages: the conceptualisation stage, where the research question was formulated; the methodological stage, where the data was collected and analysed; and the inferential stage, where inferences were made. The conceptualisation of both the qualitative and quantitative research questions, data collection and analysis occurred independently of each other, with both strands designed and implemented to answer related aspects of the same overarching research question (Teddlie & Tashakkori, 2009).

The study was divided into two phases:
In *Phase One*, the provision of family planning services to HIV-infected women and men in Northern Uganda was investigated. Using a semi-structured interview schedule, key stakeholders from the MOH, the United Nations (UNICEF and UNFPA) and non-government organisations (NGOs) were interviewed on policies, guidelines, training, drug provision, supervision of implementation and level of national commitment in terms of expenditure on integration of family planning services with HIV care and prevention services.

Phase Two comprised three distinct components.
Firstly, administrators from the three health facilities in Gulu district in Northern Uganda were asked to complete a questionnaire about the family planning services provided and the level of integration of family planning services with HIV/AIDS care and prevention services within their facilities. Secondly, 476 PLHIV attending three HIV clinics in Gulu district were interviewed using a structured questionnaire.

The 476 respondents were asked questions on their reproductive history, desires and intentions to have children and access to the family planning services in the region. Finally, there was a qualitative component which involved semi-structured interviews with 26 participants. The matrices showing the phases of the study and the study objectives and associated methodologies are in Appendix 1 and Appendix 2, respectively.

4.7 Study site

4.7.1 Uganda

Uganda, a landlocked country in East Africa, is neighboured by Sudan to the north, Kenya to the east, Tanzania to the south, Rwanda to the south-west and the Democratic Republic of Congo to the west (Uganda Bureau of Statistics & Macro International Inc, 2007). In 2011, Uganda was estimated to have a population of 32.9 million people, with 56.1% percent of the Ugandan population less than 18 years of age and 49% below 15 years of age, making it one of the youngest populations in the world (Uganda Bureau of Statistics, 2011). The structure of Uganda's very young population is reflected in the population pyramid (Figure 2), the shape of which is typical of developing countries (U.S. Census Bureau, 2010). Uganda has the second highest fertility rate in the world, with an average of 6.7 children born per woman. This is second, only to Niger in West Africa, which has an average of 7.6 children born per woman (Uganda Bureau of Statistics & Macro International Inc, 2007). According to a Central Intelligence Agency (CIA) 2010 estimate, Uganda had an estimated 47.55 births/1000 population, and a 3.563% population growth rate. Both of these rates are the second highest in the world (Central Intelligence Agency, 2010).

An estimated 14.8% of the population of Uganda live in urban regions, with the remainder residing in rural areas (Uganda Bureau of Statistics, 2011). The literacy rate (calculated as people above 10 years who can read and write) is 69% of the total population with 76% of males and 63% of women able to read and write (Uganda Bureau of Statistics, 2011). The Central region (excluding Kampala) has the highest literacy rate at 80%, while Northern Uganda has the lowest literacy rate at 59%.

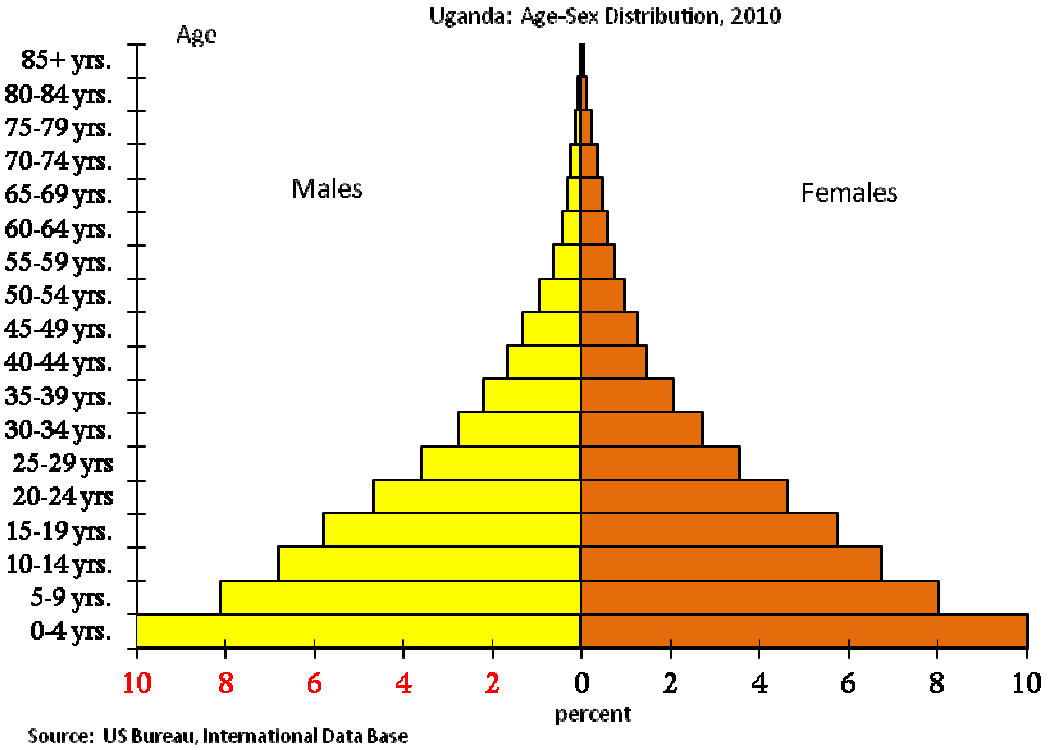

Figure 2: Population pyramid of Uganda's population 2010

Agriculture is the most important industry in Uganda, with 82% of the population working in this industry, and only 13% in the service industry. Accordingly, most Ugandans are peasant farmers with women making up the bulk of rural farmers. Uganda is a developing, third world country with a 2008/2009 Gross Domestic Product (GDP) annual growth rate of 7.0% and GDP per capita of 1200 United States dollars (USD), making it one of the most impoverished countries in the world (Uganda Bureau of Statistics, 2009). An estimated 31% of Ugandans live below the poverty line and on average, 70% of Ugandans live on less than one dollar a day.

According to the Uganda Bureau of Statistics (UBOS), the infant mortality in Uganda is 75 deaths per 1000 live births and under-five mortality is 137 per 1,000 live births, with large differences between rural and urban areas (Uganda Bureau of Statistics & Macro International Inc, 2007). The infant mortality is 68 and 88 deaths per 1000 live births in urban and rural areas respectively, while the under-five mortality is 114 and 153 respectively. The maternal mortality ratio (per 100,000 live births was 137 in 2005/6 and the life expectancy for the total population at birth is 50.4 years, with 48.8 years for males and 52.0 years for females (Uganda Bureau of Statistics, 2011).

4.7.2 Gulu District

Gulu District is one of seven districts in Northern Uganda that make up the Acholi-sub region of Uganda (See Map of Uganda in Appendix 3). The other districts are Lamwo, Amuru, Nwoya, Pader, Agago, and Kitgum. In 2006, Gulu was administratively split into two to create Gulu district and the new Amuru district, and more recently, Nwoya District was created. Gulu town, Gulu district's administrative centre, is 332 kilometres north of the capital city, Kampala, and is the economic capital of the northern region. Gulu district had a 2011 mid-year projected population of 385,600 (Uganda Bureau of Statistics, 2011). According to the 2002 Uganda census, a quarter (25%) of the population was living in Gulu town, with the remainder living either in IDP camps or in the rural areas (Government of Uganda & Uganda Bureau of Statistics, 2002).

Between 1987 and 2007, Gulu district and other surrounding districts in Northern Uganda were affected by armed conflict between the Government of Uganda (Uganda People's Defence Forces (UPDF) and Lord's Resistance Army (LRA) combatants. The brutal conflict was characterised by mass civilian displacement, child abductions, ruthless killings and maiming, and attacks on IDP camps. At the height of the war in 2005, over 1.5 million people, constituting about 90% of the population of Acholi and Lango sub-regions, were displaced into these camps (Ministry of Health Uganda, 2006) and this resulted in a complex, protracted emergency. By the time this field work was undertaken in 2009, the war had been over for two years; but many people were still living in IDP camps. Most people have now made their way back to their original homes or transition camps, though life is still very uncertain. This is because the LRA, though no longer active in Northern Uganda, have not signed the final peace agreement with the Government of Uganda (Office for the Coordination of Humanitarian Affairs (OCHA), 2011).

Mapping of the region by UNHCR has shown that there are still a few people living in camps or former camps. By November 2010, an estimated 70,000 people were still in the camps and another 70,000 people were in transit camps, that is, smaller, more transient camps, awaiting final settlement (Office for the Coordination of Humanitarian Affairs (OCHA), 2011). This group is considered very vulnerable

because it is comprised of older persons, female and child-headed households, disabled people and chronically ill people. The twenty-year civil conflict resulted in disruptions to the health care system and social infrastructure, together with the migration of skilled health workers to more stable parts of the country and limited access by the IDPs to quality health services (Ministry of Health Uganda, 2006).

Mortality and morbidity due to malaria, HIV/AIDS, tuberculosis, Ebola and diarrhoeal diseases increased significantly in the years of insurgency (Accorsi et al., 2005; Ministry of Health Uganda, 2006). During the insurgency, the crude mortality rate (number of deaths per 10,000 per day) for the Acholi sub-region was 1.54 deaths per 10,000 per day and the under five years mortality rate (UFM) was 3.18 deaths per 10,000 per day, well above the emergency threshold of 1 death per 10,000 per day and 2 deaths per 10,000 per day, respectively (World Health Organization & Ministry of Health Uganda, 2005). During this time, Northern Uganda also had the highest infant mortality rates (IMR) (106 deaths per 1,000 live births) and under-five mortality (177 deaths per 1,000 live births) with even higher rates in the IDP camps at 123 and 200 respectively (Uganda Bureau of Statistics & Macro International Inc, 2007). AIDS followed malaria as the second most common cause of death among the Acholi population during the insurgency.

In 2004, the prevalence of HIV/AIDS for North Central Uganda region was 8.2% (9.0% for women and 7.1% for men), one of the highest in Uganda and in sharp contrast to a national average HIV prevalence of 6.4% and other largely rural areas such as the West Nile (2.3%) (Ministry of Health Uganda & ORC Macro, 2006). The displacement of populations, chronic food insecurity, increase in transactional and survival sex, and rape by combatants were thought to be the key drivers of the high prevalence of HIV in Northern Uganda (Wabwire-Mangen, et al., 2009).

Northern Uganda has the poorest health and social indicators of all the regions in Uganda (Ministry of Health Uganda, 2006; Uganda Bureau of Statistics & Macro International Inc, 2007). Chronic food shortages and high levels of disease, low levels of education mean that many people in Gulu are living below the poverty line. Gulu district has the highest percentage of its population (58.1%) in the lowest quintile of wealth in Uganda, with 69.2% of IDPs in the lowest quintile and only

0.9% of females and 3.0% of males completing secondary education (Uganda Bureau of Statistics & Macro International Inc, 2007). Literacy rates among women in Northern Uganda are markedly lower than their male counterparts, 31.2% vs. 81% respectively, but also markedly lower than other women from other parts of Uganda, where literacy ranges from 41.8% in West Nile to 90.8 % in Kampala (Uganda Bureau of Statistics & Macro International Inc, 2007).

Many of the residents in Gulu live in grass-thatched houses; many have low education levels and are not formally employed. Life in both the camps and towns has been difficult and precarious for many people for a long time. Though the camps were generally protected by the UPDF, they were also at risk of rebel attacks, during which many people, including children, were abducted and taken to join the rebel forces. Overcrowding, poor sanitation (latrines are accessible to only 31% of the population) and low levels of quality water in the camps led to high levels of communicable diseases (Office for the Coordination of Humanitarian Affairs (OCHA), 2011) but also to high levels of psychosocial problems like domestic violence and abuse towards women.

Northern Uganda also had the lowest use of contraceptives by currently married women aged 15-49 years, with only 10.9% of women using family planning methods in 2006 (Uganda Bureau of Statistics & Macro International Inc, 2007). The total unmet need for family planning in the Northern region was 46% among currently married women, with 29.5% of women unable to access family planning services to help space births and 16.5% of women unable to limit their family size. Overall, only 19.1% of demand was being met in Northern Uganda, the lowest percentage in the whole country (Uganda Bureau of Statistics & Macro International Inc, 2007). The total fertility rate in Northern Uganda was 7.5 children, one of the highest in the country. Thus many of the people in Gulu, including the participants, had large families that they could not adequately support.

4.8 Quantitative arm of study

4.8.1 Health facilities and HIV Clinics

For the quantitative arm of the study, the respondents were mainly recruited from three out-patient HIV clinics at Gulu National Referral Hospital (GNRH), St. Mary's

Hospital, Lacor and The AIDS Support Organisation (TASO). The three facilities were selected because of their physical accessibility as well as time and resource constraints. The three health facilities are based in the Gulu municipality area, all within six kilometres of the town. Additional respondents were recruited from Comboni Samaritan outpatient clinic, an outpatient clinic attached to Lacor Hospital and from TASO outreach HIV clinics in Awach, Pabo and Bobi IDP camps.

Gulu National Referral Hospital is a government-owned national referral hospital with 300 beds, St. Mary's Hospital, Lacor is a Catholic mission hospital with 484 beds, and TASO clinic is a non-government, USAID-supported HIV facility with outpatient (ambulatory) and community-based services, but no inpatient services. The three facilities cater for most of the HIV-infected clients in the district, providing the most comprehensive services available in the region, including adult and paediatric HAART, PMTCT services, VCT and treatment for opportunistic infections. The facilities also provide laboratory diagnosis and follow up. The two hospitals also provide inpatient services to AIDS patients who require admission. These facilities mainly cater to patients in the surrounding areas and those able to access the outreach clinics in the IDP camps mainly run by TASO and Lacor Hospital. According to administrative records, in 2008 Gulu National Referral AIDS clinic had 1,102 registered HIV-infected clients with an average of 196 seen per week. Lacor Hospital AIDS clinic had 7,761 registered clients and on average 450 clients came every week, while TASO had 9,201 registered clients and on average 975 were seen per week.

4.8.2 Target population

The target population of interest was HIV-infected women and men in the reproductive age group (15-49 years) who were attending the three out-patient HIV clinics in Gulu district in Northern Uganda.

4.8.3 Study population

a. Sample size determination

Though there were three main dependent variables for the overall study, the desire for children among PLHIV was the primary dependent variable of interest and was used to determine the sample size for this study. Although one United States-based

study found that almost 30% of HIV-infected study participants desired to have more children despite their HIV status (Chen, et al., 2001), another study in Jinja, Uganda, found that only 7% of HIV-infected clients desired to have more children (Nakayiwa, et al., 2006). A higher proportion of 50% was used for this study, that is, it was assumed that 50% of the sample will desire to have children, and 50% will not desire to have any more children. This allows for the most conservative measure for estimating sample size. With an acceptable sampling error of 5% (de Vaus, 1991), and at 95% level of confidence and using the formula below (Kirkwood, 2000), the overall sample size was calculated as:

$$\frac{n(1-n)}{e^2} = \frac{50(100-50)}{2.5^2} = 400$$

where n is the proportion and e the required size of standard error. The formula is the formula for sample size determination for a single proportion, and sampling error is two standard errors.

The original subsample sizes per clinic were calculated as 172, 24 and 204 from Lacor, Gulu National and TASO clinics, respectively. This was in proportion to their overall clinic numbers. The Gulu National hospital sample size was increased from 24 to 100 respondents to allow for comparative analysis. The final sample size was 476 respondents consisting of 238 males and 238 females.

b. Sampling procedure

Official permission from the three health facilities was obtained to interview clients attending the outpatient HIV clinics. Recruitment of respondents started in February 2009 and ended in May 2009. Quota sampling was selected as the most appropriate method of sampling for this study because it ensured an adequate number of males and females in the different age groups for statistical analysis of the outcomes of interest, that is, family planning use, fertility desires and burden of stigma. In quota sampling, a non-probability sampling technique, participants are selected according to a fixed quota, and in this study, fixed quotas were based on age and sex (See Appendix 4). Non-proportional quota sampling further ensured that sampling would include particularly hard-to-reach groups who were usually in very small or insignificant numbers. In this study, this was necessary because male clients and those aged 15-19 years were significantly under represented at these HIV clinics and yet reproductive behaviours in male and younger PLHIV are particularly poorly

understood in Uganda. Females aged 25-44 years made up 63-72% of the HIV clinic attendees but females make up only 52% of HIV-infected persons in Uganda (UNAIDS, 2006). Thus the equal number of male and female participants in the sample was consistent with the overall HIV prevalence in the country.

Because of the lack of comprehensive client lists and appointment systems across the three participating clinics, the seven interviewers approached consecutive clients attending the HIV clinics on every HIV clinic day and asked them to participate in the study. Four interviewers recruited respondents at Lacor Hospital and Comboni outpatient HIV clinics, two interviewers recruited respondents from GNRH HIV clinic, and one interviewer recruited respondents from TASO outpatient clinic as well as TASO outreach clinics in Awach, Pabo and Bobi IDP camps. The respondents were recruited until the desired sample size was met for each quota.

c. Selection criteria

The following inclusion criteria were used for the respondents:

- HIV-infected females and males attending outpatient HIV clinics in Gulu district;
- Reproductive age: 15-49 years;
- Clients who provided informed consent

Exclusion criteria:

- Very sick clients and/or inpatients

4.8.4 Data collection procedures

The Instrument

A 121-item structured questionnaire was used to collect socio-demographic information, sexual and reproductive history, and fertility desires and intentions of the 476 respondents (See Appendices 5-8 for female and male structured questionnaires in English and Luo). Most of the questions were adopted from the 2006 Uganda Demographic and Health Survey tool (UDHS) (Uganda Bureau of Statistics & Macro International Inc, 2007) which has been used in Uganda for several demographic health surveys since 1988. The UDHS was conducted by the Uganda Bureau of Statistics (UBOS), which was technically assisted by Macro

International Inc. The UDHS tool has been translated into Luo, the main language of the region where the study was conducted, so the questions adopted from the tool were used verbatim. Thirty-three questions on stigma were adopted from the HIV/AIDS Stigma Instrument-PLWA (HASI-P) tool developed by Holzemer et al. (Holzemer, Uys, Chirwa, et al., 2007; Holzemer, Uys, Makoae, et al., 2007). These questions were translated into Luo by a person well versed in both Luo and English and her translation was checked by a second person, who back translated into English to check the accuracy.

The questionnaires were structured with pre-coded closed/forced choice questions to ease data collection, entry and analysis. The questionnaire was divided into seven sections. The first section included questions about the respondent's age, sex, religion, marital status, level of education attained, residence, and occupation. The male respondents were asked if they had more than one spouse, while the female respondents were asked if their husbands had other wives and if so, how many and what number of wife they were. The respondents who were married or cohabiting were also asked questions about their spouse's age, level of education, occupation and religion. Male respondents with more than one wife were asked the same details for each of their wives.

The second section of the questionnaire included questions on whether the respondents had ever had children, details of biological children, whether alive or dead, and their sex. The female respondents were asked if they were currently pregnant, how many months the pregnancy was if they were, and if the pregnancy was desired or not. They were also asked if they had ever miscarried, aborted or ever had a stillbirth.

The third section of the questionnaire included questions about family planning knowledge, past and current use, and source, of contraception and reasons for not using contraceptives among non-users. To determine family planning knowledge, respondents were asked to name ways or methods by which a couple could delay or avoid pregnancy. If the respondent failed to mention a particular method without being prompted, the interviewer described the method and asked whether the respondent had heard of it, and if they had ever used the method. This form of

prompting was used in case the respondent knew the method by another name or knew the method but didn't know its name. The respondents were asked if they were currently using any method to prevent further pregnancy, where they obtained contraception from and sources of information on family planning methods, methods they preferred to use, reasons for not using contraception, and whether health workers at the facility had discussed family planning with them. The married respondents and those who were in de facto relationships, widowed, divorced or separated were also asked if they had discussed family planning methods with their spouses in the past.

The fourth section on fertility preferences contained questions on the desire to have children. Respondents were asked whether they wanted to have children in the future and how many children they desired or intended to have. The female respondents who were not pregnant and all the male respondents were asked: *"Now I have some questions about the future: Would you like to have a/another child or would you prefer not to have any (more) children?"* The pregnant respondents were asked: *"Now I have some questions about the future. After the child you are expecting now, would you like to have another child, or would you prefer not to have any more children?"* Depending on the answer to this question, the respondents were asked why they wanted or did not want more children in the future. Those respondents who wanted more children were asked how soon they wanted more children, and how many they wanted and intended to have in the future. The married respondents and those who were in de facto relationships were also asked about the desire of their spouses to have children, how many children they wanted, and how important it was for their spouse to have more children. The respondents who did not want more children in the future but were not using family planning methods were asked the reason for not using family planning methods to prevent further pregnancies.

The fifth section on HIV knowledge examined the respondents' knowledge of HIV transmission and ART. The respondents were asked questions on the routes of transmission of HIV between mother and child, whether they knew of any treatment to prevent this transmission and where to obtain this therapy. They were asked questions on whether they knew of any therapy used to prolong life among PLHIV, where they had heard of this information (TV, radio, and other media). Their level of

knowledge of ART was gauged using questions such as whether they thought ART was a cure for HIV, whether ART had to be taken for life once started, and whether lack of adherence to therapy could cause development of resistance.

The sixth section on HIV history asked the respondents the length of time since their HIV diagnosis, how long they had been attending the clinic, if they were on HAART and the length of time they had been on HAART. The respondents were asked if they had disclosed their HIV status to other family members. The respondents who were married, in de facto relationships, widowed, divorced or separated were also asked if they had disclosed their HIV status to their spouse, the HIV status of their spouse and, if positive, whether they were on HAART. The respondents who had children were asked if any of their children was HIV-infected.

In the seventh section on HIV/AIDS and Stigma, the 33 questions on stigma measured two main categories of stigma namely, *received* and *internal* stigma (Holzemer, Uys, Chirwa, et al., 2007). Received stigma referred to all types of stigmatising behaviour towards a person with HIV, while internal stigma included thoughts and behaviours resulting from the person's own negative self-perception based on his/her HIV status (Holzemer, Uys, Chirwa, et al., 2007). *Received* stigma was further divided into five dimensions specifically, fear of contagion (six items), health care neglect (seven items), social isolation (five items), verbal abuse (eight items), and work place stigma (two items).

Verbal abuse related to any verbal insults or ridicule experienced by the respondents because of their HIV status and intended to harm (questions 98,103-107,109, 113) (Holzemer, Uys, Chirwa, et al., 2007). Negative self-perception (internal stigma) (questions 124-128) related to any negative self-evaluation that resulted from having HIV, while health care neglect (questions 116-122) related to any negative treatment at a health facility based on the HIV-infected status of the respondent. Social isolation related to a situation where other people limited their contact or association with PLHIV (questions 101-102, 110-112). Fear of contagion related to any behaviour that indicated that other people feared coming into close physical contact with PLHIV (questions 95-97, 99-100, 108). Workplace stigma (question 114-115) related to any negative behaviour in the workplace e.g. discrimination based on HIV

status (Holzemer, Uys, Chirwa, et al., 2007). The Cronbach alpha reliability coefficients for the HASI-P scale range from 0.76 to 0.90 (Makoae et al., 2009).

Recruitment procedures

The researcher trained and supervised seven nurses who administered the questionnaire to the respondents in the three HIV clinics and their associated outreach clinics. Interviewer administration was chosen mainly because many of the respondents did not know how to read and write. Because of the large number of interviewers, inter-interviewer variability was a concern and it was important that uniformity it was retained across the process of data collection. Thus the researcher distributed the questionnaires amongst the interviewers and the first ten questionnaires were checked for completeness and accuracy to ensure quality and correct any problems before the main survey. Every day the researcher visited the three clinics to supervise recruitment and data collection, replenish questionnaires and check with the interviewers regarding any problems they were facing, such as delays with recruitment of respondents, need for transport money to reach the IDP camps and so on.

All clients who consented to participate in the study were taken to a designated private consulting room within the HIV clinic to prevent other clinic attendees from being aware of what was going on and to ensure confidentiality. Each interview lasted between 30-40 minutes.

4.8.5 Variables

The variables chosen were based on the research questions and were mainly identified from the literature. The variables in the individual-based questionnaire represented attributes, behaviours, beliefs, attitudes and health status of the respondents and were classified as independent and dependent variables. The independent variables for desire to have children among PLHIV at the individual level included socio-demographic characteristics (age, sex, residence, education level, marital status, type of marriage, religion), number of live children, history of the death of a child, pregnancy status, HIV-infected status of the children, spousal age group, HIV status of primary partner, months since HIV diagnosis, use of HAART, months on HAART, months at the HIV clinic, HIV clinic attended, and

spouses' desire for children. Other independent variables in the study included disclosure of HIV status to spouse, PMTCT knowledge, use of family planning (contraception) and discussion of family planning methods with a health worker and spouse. The dependent variables included desire to have children, family planning use, and perceived stigma among the respondents.

4.8.6 Quantitative data entry, organisation and analysis

Quantitative data from the questionnaires was entered into Statistical Package for the Social Sciences (SPSS Inc ©) database and was cleaned and checked for errors. All data was coded, including missing data which was coded 9 or 99. These codes were not treated as valid responses and were excluded from analysis. Recoding of variables was also done, mainly to convert continuous variables into ordinal, and nominal data ease data analysis. The data was analysed using SPSS© Statistics Version 19 for Windows (SPSS© Inc, Chicago, Illinois, USA). Frequencies of all the variables were undertaken initially. Bivariate analysis was conducted to determine statistical association between key independent and dependent variables. Depending on the level of measurement of each (nominal, ordinal and interval), appropriate analytical methods were employed to provide both descriptive (cross tabulations) and inferential statistics (chi square, Fisher's test) (de Vaus, 1991). Chi-Square tests were used to determine the association between categorical variables. Pearson's Chi-Square was generally quoted, however, in the 2 by 2 tables, Yates' Correction for Continuity was used which compensates for the overestimation of the chi-square when used with a 2 by 2 table. Fischer's Exact Test was used if 20% or more cells had an expected value of less than 5 (Pallant, 2007).

Logistic regression analyses were conducted to establish significant association between independent and dependent variables of main interest. Multivariate logistic regression analysis, using a manual backward stepwise model, included all variables identified in the bivariate analysis with a p-value <0.1 (Field, 2005). In this model, all the independent variables were included in the initial model and then in a stepwise fashion, independent variables were manually removed, starting with the one least significantly associated with the outcome variable. Thus a logistic binary model was developed where the dependent variable was binary, e.g. whether or not the respondent desired children (yes/no) or whether or not the respondent was using

contraception (yes/no). Interaction terms were investigated for the variables remaining in the model.

4.9 Qualitative arm of study

4.9.1 The participants

For the qualitative arm of the study, a set number of participants were not chosen before the study started, but there were a number of inclusion criteria. The participants could be male or female, but they had to be HIV-infected, aged between 15 and 49 years, they had to live in Gulu or the surrounds and they had to be willing to participate in the study. Any clients under 15 years or over 49 years of age, any who lived outside Gulu, or any who were too ill to participate, were excluded from the study. Eventually a total number of 26 participants were selected, including 12 males and 14 females. We stopped the recruitment of participants for this arm of the study when we found that we were not collecting any more new data and the themes were reoccurring.

4.9.2 Recruitment procedures

In order to obtain interviewers and participants for the qualitative arm of the study, I approached Comboni Samaritan of Gulu, a community-based organisation in Gulu. I had previously worked with this organisation on a long-running HIV project where we had recruited over 1000 HIV-infected clients onto HAART. I was well known in this organisation, having been head of the AIDS Department and the Antiretroviral Project Coordinator at St. Mary's Hospital Lacor for almost five years. Comboni Samaritan had a long-standing relationship with the Lacor Hospital HIV clinic and some of their staff members were based there. Comboni was in charge of the community adherence program for all HIV-infected clients enrolled under Lacor's HIV HAART program.

The Director of Comboni Samaritan in consultation with other staff members, identified three HIV counsellors who recruited and interviewed the participants. The three counsellors, two males and one female, were selected because they were knowledgeable about HIV and AIDS, had extensive experience in community HIV care and support, and were sensitive to the context of the PLHIV. They had 5-10 years experience in counselling HIV clients, and one of the male interviewers was

also an enrolled nurse. The female interviewer was a retired nurse who had had over 30 years working experience providing nursing care at several hospitals in Northern Uganda, including Lacor Hospital. At the time of the research, they were all employees of Comboni Samaritan Organisation, working as community educators and counsellors.

The participants were selected using purposive sampling techniques. The three interviewers approached HIV-infected clients who they had met in the course of their counselling work for the Comboni Samaritan community outreach services. This was important because we particularly wanted HIV-infected clients in order to explore the research question in detail. We selected a sample of HIV-infected men and women who would be able to talk in detail about the desire to have children among PLHIV and what factors influenced these desires. The interviewees included HIV-infected men who had fathered children and HIV-infected women who had had children and/or pregnancies since their HIV diagnosis. As the study proceeded, we also selected participants who had not had children since their HIV status was diagnosed. I wanted to be able to make comparisons between different sexes, age groups and backgrounds so I encouraged the interviewers to recruit from a range of clients. Because of the sensitivity of the topic, I requested the female interviewer to recruit female participants and the male interviewers to recruit the male participants. This was done to minimise the impact of gender difference on the interview process. For instance the female participants may have felt uncomfortable discussing family planning and desire to have children with male interviewers.

4.9.3 Data collection procedure

I held initial discussions with the three interviewers to introduce the guide, the information sheet, the digital tape recorder, and how to conduct the interview. We discussed each of the questions and I explained how to pose the question, follow on questions, how not to lead the participants, and how to make them comfortable. I was aware that the questions were very sensitive, so it was important that the participants were comfortable with the interviewers in order for them to illicit their attitudes, beliefs and hopes for the future. Importantly, my presence in the first interview, instead of enhancing the comfort of the participant, seemed to make her even more uncomfortable. This obvious discomfort made me decide against participating in

further interviews. Moreover, the three interviewers were all collecting data at the same time and I could not have been at all the interviews, given the participants were dispersed across 20 kilometres. One interviewer did a number of his interviews with participants who lived in an IDP camp 20 kilometres from Gulu town.

4.9.4 Methods of data collection

Semi-structured interviews

The semi-structured interviews explored the participants' fertility desires and intentions and the structural/environmental, community and individual factors that enhanced or restricted their ability to plan, space and limit their family sizes. I chose this form of interview because of the sensitivity of the topic and because discretion was needed. Interviews, which lasted between one and two hours, were held in the privacy of the participants' homes and interview times were adjusted to the participants' schedules. Wherever possible, the interviewers worked within the schedule of the participants in order to avoid as much distraction as possible. If the participants had house chores to do, then the interviews were conducted around their activities. Though the interviews were held in the participants' homes, they were held out of hearing range of other family members and neighbours to ensure confidentiality, unless the participant indicated that they did not mind other family members hearing the content of the interview. All interviews were conducted in Luo, the local and major language in the region. Though a number of participants knew English, I preferred that all interviews were conducted in the local language to develop better rapport and to avoid issues of misinterpretation or misuse of words.

I had developed a set of questions as part of the semi-structured guide, but how the interviewers posed the questions depended on the flow of the interview (See Appendices 9 and 10 for the English and Luo versions of the semi-structured interview guide). There were a total of 41 questions, with nine general questions and 32 more specific, open-ended questions. Though I encouraged the interviewers to ask the same questions as much as possible, so that the answers could be compared later, I also told them that if a participant raised an important issue, they should follow up with questions to further explore that issue. We explored the following issues:

- Their desires and intentions to have children and factors influencing reproductive decision-making

- Impact of availability of PMTCT and HAART programs on fertility choices
- Their experiences of family planning service provision and its impact on fertility decisions
- Their experiences of HIV stigma and its impact on fertility decisions
- Influence of family, friends, society, medical personnel, community perceptions towards individual's child bearing desires
- The impact of the prolonged civil conflict on their reproductive decisions

Note taking and journaling by interviewers

I asked each of the interviewers to keep a journal to record the demographic information of the participant, together with observations, impressions, reactions and other significant events that occurred during the data collection phase of research. Information noted may have included reactions of the participants, interactions with family members, information about the interview setting or home environment, attitudes and behaviour of participants. This was done with a view to these journals being a useful source of supplementary information (Rudestam & Newton, 2007).

Maintaining a reflexive journal

I also kept two of my own journals. In my personal journal, I took notes about the challenges I was experiencing during selection of the interviewers, recruitment of participants and delays with the ethical approvals, together with other hurdles such as my car breaking down and my financial difficulties. In the formal journal I wrote reflective notes to record what I saw and heard in the research setting and also reflections on the methodological aspects of the study. I also reflected on my role in the research process and how I may have, as a former doctor at Lacor Hospital and well known to a number of the participants, influenced the data collection process. I will expound on this later in this Chapter in the section on ethics.

Key informant interviews

United Nations Population Fund (UNFPA) staff members, managers of Marie Stopes International, Uganda (MSIU) and Reproductive Health Uganda (RHU), MOH officials and Family Health International (FHI) were interviewed in order to collect information on the availability of HIV and family planning services in Gulu. These

officials were also asked about funding for family planning services in the region, whether there were specific programs for PLHIV and whether they funded training of health workers. (See Appendix 11 for the guideline of the interview).

Health facility tool

The interviewers arranged for the health facility administrators to complete a health facility tool modelled on the Refugee Reproductive Health needs assessment field tool (Reproductive Health for Refugees (RHR) Consortium, 1997) and the Service Availability Mapping of Northern Uganda tool (Ministry of Health Uganda, 2006). The former tool was developed by the Reproductive Health Response in Conflict Consortium (RHRC), a consortium of organizations working in conflict and post-conflict regions. The tool was created to determine existing health facility capacity to meet the reproductive health needs of refugees and internally displaced persons, and also what material and human resources were needed to upgrade service delivery to these populations. This tool was therefore chosen because the health facilities were in a post-conflict region and this enabled us to collect data on the reproductive health and family planning services available at the selected health facilities.

4.9.4 Data recording and transcribing of interview data

The interviewers asked the participants if the interviews could be recorded to ensure there was an accurate and complete verbatim recording of both the researcher's questions and participant's responses i.e. to ensure fidelity to the data collected. Most of the participants accepted their interviews to be audio taped. However, some of the participants did not consent to having their interview recorded and the interviewers therefore had to write their responses. We respected their wishes not to be recorded, though this may have affected the ability to record their interviews verbatim. While taking notes is less desirable, as it is not possible to record everything said, we did not coerce the participants. The interviewers therefore had to try to write as much as they possibly could. I also asked the interviewers to take notes which would help us later during the transcribing of the interviews. All three interviewers listened to the recordings and transcribed the audio taped data into English. When the interviewers completed transcription of their interviews, I listened to the tapes to check the translation and also to get a feel for all the interviews.

4.9.5 Qualitative data analysis

The process of analysis drew inspiration from thematic content analysis and was guided by the Framework Approach to Analysis (Lacey & Luff, 2007; Pope, Ziebland, & Mays, 2000). The aim of the analysis was to produce a succinct and reliable matrix of key themes (Reis & Judd, 2000) and to develop concepts from the data rooted in the reality of human experience (Sim & Wright, 2000). I undertook the data analysis in several phases:

Phase 1: In the field – first level analysis

- All three interviewers listened to the recordings in the field in Northern Uganda and transcribed the audio taped data into English. Later, I listened to the tapes myself to check the translation for accuracy and also to get a feel for all the interviews.
- I met with the interviewers at least three times a week to discuss the data they had collected, any concerns they had and what their main findings were.
- If a key theme evolved or developed with any one interviewer, I contacted the other two interviewers to ask them to explore the theme further with subsequent participants.
- Therefore – in an informal manner and taking into account the contextual field realities – some of the developing themes informed further data collection.
- I started to write memos while still in the field – I read my reflections and field notes several times to grasp their meaning and to record thoughts evoked by the field notes.
- Due to complexities in the field, including lack of computers and lack of computer knowledge among the interviewers, I conducted formal data analysis after data collection.

Phase 2: Open Coding of Interview data – 2nd level analysis

- When I returned to Perth, I imported typed transcripts into NVivo8© (QSR International Pty Ltd) in order to assist with the process of analysing the data.
- I also played the recordings back in order to try to immerse myself in the interview setting, thereby giving context to what I was reading and allowing me to listen to the intonations and language used during the interview. I read and re-

read all the transcripts to gain familiarity with the data, reading line-by-line through the whole transcript.

- Because I had three major research questions, in order to assist with analysis I decided to read each transcript based on answering each of those research questions.
- While reading the words, phrases, sentences and expressions from the transcripts, I began to create analytical categories, a process otherwise known as coding. This systematic reading and coding is also known as open coding (Bazeley, 2007). I coded each interview transcript, line-by-line. Though sometimes strenuous, line-by-line coding, a process of naming each line of written data, allows a person to explore the data in detail, whilst remaining open to the data. This process also prevents a person from superimposing their ideas onto the data (Charmaz, 2006).

Phase 3: Emerging themes and developing a thematic framework- 3rd level analysis

- After coding each transcript, I identified the key issues and core themes that were emerging. I reviewed the transcripts again to determine the sub-themes that could be collated together to form major themes.
- After developing themes, I looked through the transcripts again to look for variations according to age and sex, and to look for conditions under which particular categories or themes arose.
- I developed a separate thematic framework for each major research question. Thus a coding framework was developed to identify dominant themes and subthemes relating to experiences of stigma, fertility desires and family planning experiences.

Phase 4: Higher level analysis drawing on the conceptual framework and deductive and inductive approaches

After I had inductively created themes, I returned to the literature to compare and refine the themes I had developed.

- For experiences of stigma I compared my themes with themes used within the Conceptual Framework of HIV/AIDS Stigma developed by Holzemer et al. (2007), the results of which are presented in Chapter 6.
- For the desires to have children and experiences of family planning, I adopted some of the categories from the literature, that is, *a priori* categories, while other themes emerged from the data. Thus I constantly returned to the substantive literature and interview data, which allowed me to compare and validate some of my findings, use some of the themes and to refine the analysis of the data.
- I read transcripts repeatedly and selected cases and quotes that illustrated the themes (Miles & Huberman, 1994). The qualitative findings are presented in detail in Chapters 5, 6, and 7.

4.9.6 Triangulation

According to pragmatists, triangulation techniques can be successfully applied to all mixed-methods designs (Tashakkori & Teddlie, 1998). Greene, Caracelli, and Graham (1989) stated that the five reasons for conducting mixed-methods studies are triangulation, complementarity, development, initiation, and expansion. In this present study, the aim of complementarity provided the justification for the mixed-methods approach. As the aim was to complement findings, I sought elaboration, enhancement, and clarification from the results of each method.

Patton (2002, p. 247) advocated that "triangulation strengthens a study by combining methods". Combining data is also more likely to capture a more comprehensive picture of the setting (Neuman, 2003; Yin, 2003). As proposed by Tashakkori & Teddlie (2003, p. 545), I was guided by four principles fundamental to triangulation. The first principle of a "need for a clearly focused research question" underpinned the study. The second principle was "the complementary nature of the strengths and weakness of the chosen quantitative and qualitative methods". The strength of mixed methodology combined the two forms of methodology to seek convergence of results. The quantitative data "provided for generalisability" whereas qualitative data offered information about the context and allowed for the voices of participants in post-conflict Northern Uganda to be presented. The third principle was the "relevance of the methods to the nature of the phenomenon" in this case, a complex society and the need to appreciate the environments that PLHIV live in. The fourth

principle was "the need for continued evaluation of the chosen methodological approach" in order to better understand processes.

Methodological Triangulation

I used methodological triangulation to enhance the internal validity and overall dependability of the study (Barbour, 2001) and in an attempt to improve the probability that the findings and interpretations would be considered credible (Golafshani, 2003). The interviewers and I also undertook multiple data-gathering procedures that included a questionnaire, semi-structured interviews with PLHIV and key informants, continual detailed observations, documentary data collection, a literature review and memo writing. All of these were undertaken concurrently throughout all stages of the study, which facilitated triangulation and allowed for interview and field data to be "combined and …to make better sense of the other" (Silverman, 2006, p. 235).

4.9.7 Rigour in research

Golafshani (2003) emphasised the concepts of reliability, validity, trustworthiness, quality and rigour to discern good research from bad research, and mentioned that improvement of these stringent parameters is a critical factor in any research. I have drawn on these concepts to compare the rigour criteria in terms of this study as explained in Figure 3 below.

Ensuring rigor in qualitative research

According to Brown (2005), sound qualitative research is judged in terms of its dependability, credibility, confirmability and transferability. Other qualitative researchers consider trustworthiness to be an important component, as it demonstrates reliability and validity (Cohen & Crabtree, 2008; Graneheim & Lundman, 2003). To enhance the credibility and overall trustworthiness of this study, I employed a range of techniques (Morrow, 2005). Bashir, Afzal and Azeem (2008)

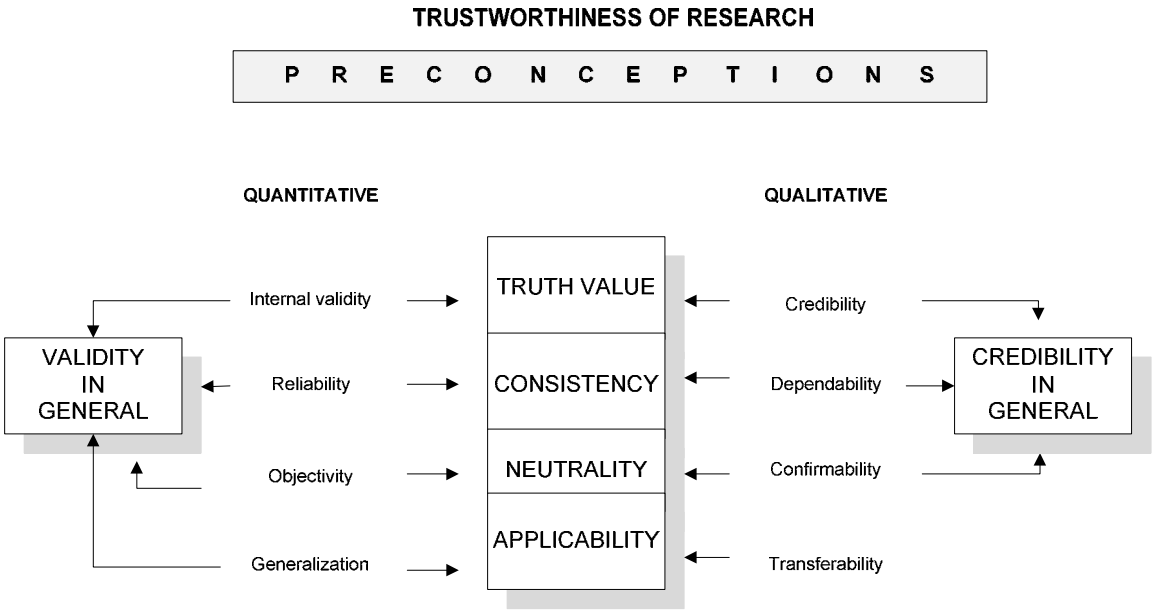

Figure 3: Indicators to describe scientific rigour in research

Adapted from Hamberg, Johansson, Lindgren & Westman (1994, p. 178)

proposed that pragmatic validation of qualitative research implied finding plausible, credible and trustworthy outcomes so that the data can be defended against reasonable challenge. While these criteria are more commonly mentioned for rigour in qualitative research, Table 4 illustrates the techniques to ensure trustworthiness during and following completion of the research.

I took steps throughout the data collection and analysis processes to establish trustworthiness of the method and credibility with respect to the findings (Denzin & Lincoln, 2008). These steps included verification strategies such as systematic checking of data and ongoing interpretation of data to enhance reliability and validity. I also conducted an audit trail, as discussed by Patton (2002), ensuring methods and data were documented so that the analysis of the data could be confirmed and replicated by other researchers. Validity was enhanced by de-briefing with key informants and expansion or clarification of issues that emerged during data analysis (Sharts-Hopko, 2002).

Use of an Audit Trail

I produced an orderly and detailed description of the study (an audit trail) to allow other researchers to replicate the study (Shenton, 2004). My aim was to supply sufficient descriptive data to make judgments possible and to facilitate transferability of the study (Brown, 2005) by providing a 'thick' and detailed description.

Table 4: Techniques to ensure the trustworthiness of qualitative research

Traditional criteria	Trustworthiness criteria	Methods for meeting trustworthiness criteria
Internal validity	Credibility	Activities in the field that increase the probability of high credibility • Recorded interviews for adequacy • Member checks • Triangulation of data types to establish validity
External validity	Transferability (Fittingness)	Detailed (thick) description of structures and processes revealed in the data
Reliability	Dependability (Auditability)	Purposive sampling Informants' confidentiality protected
Objectivity	Conformability (Audit trail)	Explicit separation of 1st order and 2nd order of findings Reporting data management and findings clearly and meticulously Verbatim transcription of interviews.

Source: Adapted from Lincoln and Guba (1985, p. 328) and Shah and Corley (2006, p. 1830).

Peer debriefing

I fulfilled the criterion for peer debriefing by having the transcripts assessed by independent transcribers to assess for consistency and accuracy of interpretation. On numerous occasions throughout the research process, I consulted with my supervisors and a selection of my trusted peers for debriefing purposes. I also presented the research methodology, findings and writings for peer group review and critique at professional meetings, conferences and colloquiums.

Prolonged Engagement

The notion of prolonged engagement was satisfied by my six-month field visit to Northern Uganda, between January 2009 and June 2009. This gave me adequate time to familiarise myself with the research settings, train survey administrators and interviewers, and conduct the interviews.

Reflective Journal

According to Cohen & Crabtree (2008) one of the hallmarks of good research is reflexive processing through the use of a journal (p. 333). An essential component of any qualitative research study is the use of a reflective journal. Reflective journals ensure people talk about their own "thoughts, beliefs and behaviours" (Janesick, 1999, p. 521). By writing during this study, I collected fresh and original information, which helped add to the data for later analysis, what Silverman (2006) called "writing in the moment". The journal also provided information which helped me with cultural and research understanding.

4.10 Ethical considerations

I obtained ethical approval from the Curtin University Human Research Ethics Committee, the Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology prior to the commencement of the study.

Informed consent

In order to ensure that participants were able to give informed consent, the interviewers explained the objectives, procedures and implications of the study. The participants were allowed to reach a rational, autonomous decision and were not coerced to join the study. Clients aged between 15-18 years were considered mature minors, and hence capable of providing informed consent, if they were attending the HIV clinic alone and deemed capable of making autonomous decisions. The interviewers read out the translated information sheet and consent form to the participants (see Appendices 12-18 for information sheets in both English and Luo for participants and officials, and Appendices 19-23 for the consent forms).

Right to withdraw

The interviewers also informed the participants that they were free to withdraw at any stage in the study without any negative consequences in terms of access to care and support. The interviewers ensured that the participant's wishes, dignity and welfare were respected. Depending on their ability to write, participants who consented to participate in the study either signed or thumb-printed the consent form.

Confidentiality

I ensured that confidentiality was maintained and no sensitive information about individuals was accessible to other study participants, health workers or the general public. The interviewers held all the structured interviews in a private room in the HIV clinic area, while the semi-structured qualitative interviews were held in the privacy of the participants' homes. During the qualitative interviews, I asked the interviewers to ensure that the participants' family members were not privy to what the interview was about. The interviewers would wait to resume the interview if there was any interruption from children, neighbours or other relatives in the vicinity, which happened frequently as the interviews were held at their homes.

Minimisation of harm

I was very much aware that psychological harm could have occurred because the study involved an examination of individuals' attitudes, beliefs and behaviour relating to a particularly sensitive issue. This, in turn, could have uncovered feelings of guilt, especially as regards HIV transmission to spouses, other sexual partners and future children. I emphasised to the interviewers the importance of ensuring that the questions posed and the manner in which they were posed were sensitive in order to limit the possibility of arousal of feelings of guilt. The interviewers advised participants that counselling services were available and would be provided by senior counsellors at the Comboni Samaritan. Its staff members have vast experience with psychosocial support, community-based care and HAART therapy of HIV-infected clients.

Being conscious of power imbalance between the participants and I

While the study adhered to the ethical principles of respect for autonomy, respect of persons, beneficence, non-maleficence and justice, I had two major concerns that I continued to reflect upon even after data collection, analysis and even during the

writing stage. Before and during data collection, I had to reflect on the possibility that the participants would feel coerced to participate in the study. For five out the nine years I worked at Lacor Hospital, I was the Head of the HIV Department and HIV clinic. As head of the clinic I oversaw the management of all HIV clients. In particular, I was the ART project coordinator and had managed clients' enrolment onto HAART. Because HAART is a life saving therapy and only a minority of clinic attendees were enrolled on therapy, participants may have felt that non-participation could compromise the quality of health care services they received and or affect their enrolment onto HAART. At the time of the study I was no longer an employee of the hospital or head of the project, but I still had strong relationships and contacts with all the doctors, nurses and dispensers in the clinic. Also during the study, I used nurses to recruit and interview participants which might have influenced the clients' decision to participate in the study.

In her book on researching vulnerable people, Liamputtong (2007) cautioned researchers to be aware of power imbalance between researchers and participants, particularly those who are vulnerable. I was aware that HIV-infected people are vulnerable because of their chronic ill health, their heavy reliance on health workers and high levels of stigmatisation. To counter this effect, I maintained a distance from the clinics throughout the data collection, only going in to replenish the questionnaires or have discussions with the interviewers. My wish to attend the home-based qualitative interviews was not realised beyond the first interview because the participant looked uncomfortable with my presence, and refused to sit on a chair, preferring to sit on a mat on the ground in front of me. When I asked to sit on the mat with her, she vehemently refused, asking me to sit on the chair she had provided for me. Though the interview proceeded, I felt that my position in relation to her (doctor-patient) would have had an effect on her responses and any other interviews I attempted to attend. This was a scenario which made the power imbalance between the participants and me very apparent, which could have affected some of the data we collected.

I was also aware of the possible harm that the research question could bring and I had to balance the need to ask the question and the resultant benefit of the knowledge gained against the possibility of harm to the participants. Sensitive researchers have

to weigh these issues carefully whilst considering possible harm during, and even long after, the research process (Liamputtong, 2007). I am conscious that I have to be careful that the way I write and disseminate the findings neither harms the community nor reinforces stereotypes or stigmatisation towards PLHIV. Liamputtong contended that research among vulnerable people is necessary and sometimes it is the first and only time that they have an opportunity to voice their concerns and have their issues resolved. Therefore I remain aware that it is important for me to use the findings to improve the health conditions of the participants and other HIV-infected people.

4.11 Data Storage

All quantitative data was entered into SPSS© while I was in Uganda, and all paper records were transported to Perth, Australia in sealed boxes. I have ensured that all paper records, including questionnaires, handwritten transcripts, interview notes and code sheets are stored in a secured filing cabinet in my office. Questionnaires do not contain any identifiable information such as the participants' names, but only codes. Documents that link the names with code numbers are presently stored in locked cupboards and are only accessible by me. All electronic data (SPSS© databases and NVivo8© databases) is stored on a password-protected computer without identifiers and is only accessible to me. Electronic data is backed up on portable hard disks, in case the databases are corrupted. I will ensure that all of this data is kept securely for at least five years, after which it can be destroyed.

4.12 Summary of the Chapter

This chapter has provided the rationale for the study, the study design, and the qualitative and quantitative methods used in the study. The next chapter presents the quantitative and qualitative findings of the fertility desires of people living with HIV in Northern Uganda.

CHAPTER 5: FERTILITY DESIRES OF PLHIV IN GULU DISTRICT, NORTHERN UGANDA

5.0 Introduction to the Chapter

This chapter presents the summary data on the 476 respondents' sociodemographic characteristics, reproductive history, fertility preferences, HIV knowledge, and HIV history. The quantitative findings pertaining to the fertility desires of the 476 PLHIV are then presented in the form of univariate, bivariate and multivariate statistics. In the last section of this chapter, the qualitative findings of the fertility desires of the 26 participants are presented.

5.1 Quantitative arm of the study

5.1.1 Description of the sample

5.1.1.1 Sociodemographic characteristics of the 476 respondents

This section summarises the social demographic characteristics of the 476 respondents who were recruited from the three health facilities in Gulu District. The statistics for this demographic information is summarised in Tables 5 (clinic attended, sex, residence, religion) and Table 6 (education, marital status and occupation). In Table 6, the characteristics were analysed by sex to determine if there were any significant differences between the male and female respondents.

One hundred and sixty-eight (35.3%) of the respondents were recruited from St. Mary's Hospital Lacor, 210 (44.1%) were recruited from TASO while 98 respondents (20.6%) were recruited from Gulu National Referral Hospital. An equal number of male and female respondents were recruited for this study, that is, 238 males and 238 females. Two hundred and thirty respondents (48.3%) were living in urban areas (towns and trading centres), 204 (42.9%) in rural areas and 41 (8.6%) were living in the IDP camps. The mean age of the respondents was 32.2 years, with a standard deviation (s.d.) of 9.9 years, and 340 respondents (71.5%) were Roman Catholic.

Table 5: Sociodemographic characteristics of PLHIV in Gulu District, Uganda, February-May 2009: Clinic attended, Sex, Residence, Age group and Religion

Characteristic	Number	Percent
Clinic attended		
Lacor	168	35.3
TASO	210	44.1
GNRH	98	20.6
Sex		
Male	238	50.0
Female	238	50.0
Residence		
Town	201	42.2
Trading centre	29	6.1
Village	204	42.9
IDP camp	41	8.6
Other	1	0.2
Residence		
Urban	230	48.3
Rural	204	42.9
IDP camp	41	8.6
Other	1	0.2
Age group (years)		
15-19	68	14.3
20-24	68	14.3
25-29	68	14.3
30-34	68	14.3
35-39	68	14.3
40-44	68	14.3
45-49	68	14.3
Religion		
None	2	0.4
Roman Catholic	340	71.5
Anglican	100	21.1

Characteristic	Number	Percent
Muslim	12	2.5
Pentecostal	16	3.3
SDA	1	0.2
Missing data	5	1.0

GNRH, Gulu National Referral Hospital; IDP, Internally displaced people; SDA, Seven Day Adventists; TASO, The AIDS Support Organisation

Three hundred and ninety-one respondents (82.1%) had attended school, although the majority i.e. 45.9% (179/390) had received less than seven years of formal education. Only 25 respondents (6.4%) had attained post-secondary education, which is 14 years or more of education. Significantly more male respondents had attended school than female respondents: 222 (93.3%) of the male respondents had ever attended school, while 169 (71.0%) female respondents had ever attended school. Seventy-six respondents (15.9%) had never married, 236 respondents (49.6%) were either married or in de facto relationships, while 164 respondents (34.5%) were divorced, separated, or widowed. There were statistical differences in marital status by sex, with 64.3% of the male respondents in stable relationships compared to only 35.3% of the female respondents.

Of the respondents who were in stable relationships, 169 respondents (71.6%) were in monogamous relationships, while 67 respondents (28.4%) were in polygamous relationships. There was also a significant difference between the male and female respondents, with 79.7% versus 56.6% in monogamous relationships, respectively. Thus a high percentage of the married female respondents in this study (43.4%) were in polygamous relationships. Two hundred and twenty-two respondents (47%) were peasant farmers, 68 respondents (14.8%) were housewives, 49 respondents (10.4%) were students, while only 25 respondents (5.1%) were professionals.

Table 6: Sociodemographic characteristics of PLHIV in Gulu District, Uganda, February-May 2009: Education, relationship status and occupation

Characteristic	Total		Males		Females		p value
	n	(%)	n	(%)	n	(%)	
Education							
Ever attended school	391	(82.1)	222	(93.1)	169	(71.0)	**< .001**
Level of education							**< .001**
No education	85	(17.8)	16	(6.7)	69	(28.9)	
Some primary education	179	(37.5)	90	(37.8)	89	(37.2)	
Completed primary education	84	(17.6)	53	(22.3)	31	(13.0)	
Some secondary education	87	(18.2)	52	(21.8)	35	(14.6)	
Completed secondary	16	(3.4)	10	(4.2)	6	(2.5)	
More than secondary	25	(5.2)	16	(6.7)	9	(3.8)	
Missing data	1	(0.2)	1	(0.4)	-		
Relationship status							**< .001**
Single	76	(15.9)	48	(20.1)	28	(11.8)	
Married/De facto	236	(49.6)	153	(64.0)	84	(35.3)	
Separated/Divorced/Widowed	164	(34.5)	38	(15.9)	126	(52.9)	
Relationship status							**< .001**
Stable (married/de facto)	236	(49.6)	153	(64.3)	84	(35.3)	
Not stable (single/ separated/ divorced/ widowed)	240	(50.4)	85	(35.7)	154	(64.7)	
Polygyny (if married or de facto)							**< .001**
Monogamous	169	(71.6)	122	(79.7)	47	(56.6)	
Polygamous	67	(28.4)	31	(20.3)	36	(43.4)	
Number of wives [a] /number of wife [b]							
1/ 1st			122		12		
2/ 2nd			27		17		
3/ 3rd			4		4		
5th					2		
Occupation							**< .001**
Not employed	22	(4.6)	17	(7.1)	5	(2.1)	

Characteristic	Total		Males		Females		p value
	n	(%)	n	(%)	n	(%)	
Business	36	(7.6)	7	(2.9)	29	(12.3)	
Police/Military	18	(3.8)	18	(7.6)	-		
Student	49	(10.3)	27	(11.3)	22	(9.3)	
Peasant farmers	223	(47.0)	133	(55.9)	90	(38.1)	
Housewife	68	(14.3)	-		68	(28.8)	
Professionals	24	(5.1)	10	(4.2)	14	(5.9)	
Other	34	(7.2)	26	(10.9)	8	(3.4)	

[a] calculated for men in married or de facto relationships; [b] the number position of the female respondent in the polygamous relationship

5.1.1.2 Sociodemographic characteristics of the spouses of the respondents

The statistics on spouses' ages, education, occupation, and religion are summarised in Table 7. As described in Chapter 4, this data was only collected for those respondents who were married or in de facto relationships. Overall, 65.2% of the respondents' spouses were aged between 25 and 39 years of age. For the majority of the male respondents (71.0%), their spouses were aged between 25 and 39 years. The majority of the female respondents' spouses were aged between 30 and 49 years. One hundred and forty-four spouses of the respondents (70.2%) had ever gone to school and there was a significant difference between the education status of the spouses of the male and female respondents. Only 58.2% of the spouses of the male respondents had gone to school in comparison to 88% of the spouses of the female respondents. The majority of the spouses of the male respondents (60.6%) had less than seven years of education, while the majority of the spouses of the female respondents (37.0%) had at least seven years of education. The majority of the spouses of the respondents were housewives (40.0%) and then peasant farmers (30.7%). Most of the spouses of the male participants were housewives (67.2%) while the majority of the spouses of the female respondents were peasant farmers (45.8%). The majority of the spouses were Roman Catholic (76.6%) followed by the Anglican faith (17.6%).

Table 7: Sociodemographic characteristics of spouses of PLHIV in stable relationships in Gulu District, Uganda, February-May 2009: age groups, education, occupation and religion.

(Total n = 237 respondents)

Characteristic	Total		Males		Females		p value
	n	(%)	n	(%)	n	(%)	
Age groups (years) [a]							**< .001**
15-19	5	(2.7)	4	(3.3)	1	(1.6)	
20-24	22	(12.0)	20	(16.5)	2	(3.2)	
25-29	37	(20.1)	30	(24.8)	7	(11.1)	
30-34	41	(22.3)	28	(23.1)	13	(20.6)	
35-39	42	(22.8)	28	(23.1)	14	(22.2)	
40-44	20	(10.9)	7	(5.8)	13	(20.6)	
45-49	17	(9.2)	4	(3.3)	13	(20.6)	
Age groups [a]							**< .001**
Less than 30 years	63	(34.4)	53	(44.2)	10	(15.9)	
30 years and more	120	(65.6)	67	(55.8)	53	(84.1)	
Education [b]							**< .001**
Yes	144	(70.2)	71	(58.2)	73	(88.0)	
No	57	(27.8)	49	(40.2)	8	(9.6)	
Don't know	4	(2.0)	2	(1.6)	2	(2.4)	
Level of education							**0.003**
Some primary education	63	(43.8)	43	(60.6)	20	(27.4)	
Completed primary education	24	(16.7)	10	(14.1)	14	(19.2)	
Some secondary education	41	(28.5)	14	(19.7)	27	(37.0)	
Completed secondary	2	(1.4)	0	(0.0)	2	(2.7)	
More than secondary	11	(7.6)	3	(4.2)	8	(11.0)	
Occupation							**< .001**
Not employed	8	(3.9)	2	(1.6)	6	(7.2)	
Business	14	(6.8)	8	(6.6)	6	(7.2)	
Police/Military	7	(3.4)	0	(0.0)	7	(8.4)	
Student	2	(1.0)	2	(1.6)	0	(0.0)	

Characteristic	Total		Males		Females		p value
	n	(%)	n	(%)	n	(%)	
Peasant farmers	63	(30.7)	25	(20.5)	38	(45.8)	
Housewife	82	(40.0)	82	(67.2)	0	(0.0)	
Professionals	12	(5.9)	1	(0.8)	11	(13.3)	
Religion							**0.034**
Catholic	157	(76.6)	10 0	(82.6)	57	(67.9)	
Anglican	36	(17.6)	16	(13.2)	20	(23.8)	
Muslim	5	(2.4)	1	(0.8)	4	(4.8)	
Pentecostal	3	(1.5)	3	(2.5)	0	(0.0)	

[a] missing data for 53 participants; [b] missing data for 32 respondents

5.1.2 Reproductive history

This section summarises the reproductive history of the respondents. The data on whether they had ever given birth, how many children they had, what the sex and age of their children were and if their children were still alive or dead, and the number of female respondents who were pregnant are summarised in Table 8.

The median number of children among the respondents was three children (interquartile range (IQR) 1-5). The median number of children among the males was four (IQR 1-5) while it was three among the females (IQR 2-5). The number of respondents who had ever had children was 397 (83.8%). There was a significant difference between the number of the male and female respondents who had ever had children, with a higher proportion of the female respondents (88.1%) having had children than the male respondents (79.4%). Among the respondents who had ever had children, 137 respondents (34.9%) had ever lost a child. There was a significant difference between males and females, with a higher proportion of female respondents having ever lost a child in comparison to males (41.6% versus 27.4% respectively). Eighteen (7.8%) of the female respondents were pregnant at the time of interview.

5.1.3 HIV Knowledge

In Section 5 of the questionnaire, respondents were asked several questions to gauge their knowledge of HIV, its routes of transmission, PMTCT, ART and sources of treatment for HIV/AIDS. The results are summarised in Table 9. The majority of respondents, both male and female, had good knowledge of how HIV is transmitted from HIV-infected mothers to their infants. Overall, 75.7%, 91.8% and 94.7% of respondents knew that HIV can be transmitted from mother to child during pregnancy, during delivery and while breastfeeding, respectively. There was no significant difference between the male and female respondents. The majority (89.1%) also knew that there was therapy available to reduce the transmission of HIV to children and 97.2% of these respondents knew where to obtain these drugs. There was a significant difference between the males and females with more males (99.1%) knowing where to source PMTCT therapy than females (95.2%).

Table 8: Reproductive history of PLHIV in Gulu District, Uganda, February-May 2009

Characteristic	**Total**		**Males**		**Females**		
Median number of children (IQR range)	3	(1-5)	4	(1-5)	3	(2-5)	
Mean number of children (s.d.)	3.62	(2.88)	3.76	(3.24)	3.47	(2.47)	
Minimum number of children	0		0		0		
Maximum number of children	21		21		13		
Characteristic	**Total**		**Males**		**Females**		**p value ***
	n	(%)	n	(%)	n	(%)	
Respondents who have ever had a child [a]	397	(83.8)	189	(79.4)	208	(88.1)	0.010
Respondents who have ever lost a child [b]	137	(34.9)	51	(27.4)	87	(41.6)	0.003
Currently pregnant			N/A		18	(7.8)	

IQR, interquartile range; s.d, standard deviation; [a] data missing for two respondents; [b] data missing for three respondents, calculated for only those who had children; *p value calculated using Chi-square

The majority of the respondents (97.9%) knew that there were treatments available for prolonging the life of people infected with HIV and a majority of respondents also knew where to obtain this therapy (96.8%). Most of the respondents obtained their information on ART from the radio (92.3%), newspapers (27.0%) and signs or pamphlets (23.4%). Fewer obtained their information from TV (11.3%) or Video (16.6%). In more detailed questioning about the role of ART, 76.0% of the respondents agreed that ART is not a cure for HIV infection. Only 7.9% of respondents thought that people receiving HAART could not transmit HIV to others. The majority of the respondents (97.6%) agreed that once started on therapy, HIV-infected patients had to continue HAART for the rest of their lives but only 3.6% said that patients should wait until they have symptoms before they saw a health worker about HAART. Ninety five percent of respondents agreed that failure to adhere to therapy could lead to development of resistance of the HIV virus to HAART. This showed a high level of understanding around HIV and the role of ART among the study population.

Table 9: HIV Knowledge among PLHIV in Gulu District, Uganda, February-May 2009

	Total		**Males**		**Females**		**p value***
	n	(%)	n	(%)	n	(%)	
Knowledge of whether HIV is transmitted							
During pregnancy	358	(75.7)	174	(73.7)	184	(77.6)	0.544
During delivery	437	(91.8)	219	(92.0)	218	(91.6)	0.618
During breastfeeding	450	(94.7)	224	(94.5)	226	(95.0)	0.336
Knowledge of drugs for PMTCT							0.232
Yes	423	(89.1)	215	(90.3)	208	(87.8)	
No	24	(5.1)	8	(3.4)	16	(6.8)	
Don't know	28	(5.9)	15	(6.3)	13	(5.5)	

	Total		Males		Females		p value*
	n	(%)	n	(%)	n	(%)	
Knowledge of source of drugs for PMTCT							**0.017**
Yes	410	(97.2)	212	(99.1)	198	(95.2)	
No	12	(2.8)	2	(0.9)	10	(4.8)	
Heard of ART	466	(97.9)	231	(97.1)	235	(98.7)	0.437
Knowledge of where to obtain ART	452	(96.8)	221	(95.7)	231	(97.9)	0.275
Sources of information for ART							
Radio	431	(92.3)	221	(95.3)	210	(89.4)	**0.027**
TV	50	(11.3)	28	(12.6)	22	(10.0)	0.484
Newspaper	120	(27.0)	78	(35.0)	42	(19.0)	**< .001**
Sign/Pamphlet	103	(23.4)	63	(28.4)	40	(18.3)	**0.017**
Video	73	(16.6)	42	(19.0)	31	(14.2)	0.223
Knowledge of ART:							
Agreed with:							
a) ART is not a cure for the AIDS virus.	355	(76.0)	179	(77.5)	176	(74.6)	0.153
b) A person receiving ART cannot transmit the virus to others	37	(7.9)	21	(9.1)	16	(6.8)	0.515
c) Once ART is started, a patient must continue treatment for the rest of his/her life.	455	(97.6)	226	(97.8)	229	(97.4)	0.953
d) People who know they are HIV-positive should wait until they feel sick to see a doctor or nurse about ART.	17	(3.6)	11	(4.7)	6	(2.6)	0.080

	Total		Males		Females		p value*
	n	(%)	n	(%)	n	(%)	
e) Failing to follow ART as directed can make the AIDS virus become stronger and even harder to control.	444	(94.9)	223	(96.1)	221	(93.6)	0.468

ART, antiretroviral therapy; PMTCT, Prevention of Mother-to-Child Transmission; *p value calculated using Chi-square

5.1.4 HIV History

This section presents statistics summarising the respondents' HIV history. This includes data on how long they had known of their HIV diagnosis, how long they had been attending the HIV clinic and whether they were receiving HAART. The respondents who were married, in de facto relationships, divorced, widowed or separated were asked about the HIV status of their spouse, whether their spouse was on HAART and whether they had disclosed their HIV-infected status to their spouse. The results of this section are summarised in Table 10.

One hundred and thirty-seven (29.1%) respondents had known their HIV diagnosis for less than 12 months. There was a significant difference between the male and female respondents, with a higher proportion of females having known their HIV status for longer than 24 months in comparison to male respondents: 59.2% versus 48.9%, respectively. Most of the respondents had been attending the clinics for less than 12 months (38.6%). A higher proportion of female respondents in comparison to the male respondents had been attending the clinics for longer than 24 months, 49.6% versus 40.3% respectively. The female respondents were asked if they were pregnant at the time of their HIV diagnosis and 42 respondents (18.7%) confirmed they were.

There were 236 respondents (49.8%) on HAART, including 107 males and 129 females. Though there were a higher proportion of female respondents on HAART than male respondents: 54.4% versus 45.1%, respectively, it was not statistically significant (Yates Correction for Continuity = 3.722; d.f. = 1, p = .054). Of those

respondents on HAART, 216 (92.7%) said they felt better, including 104 males and 112 females. Most of the respondents had been on HAART for less than 12 months (27.4%). Of the respondents who were married, in de facto relationships, divorced, widowed or separated, 53.7% (213/397) had an HIV-infected spouse i.e. they were sero-concordant, while 49 respondents (12.3%) had an HIV-negative spouse i.e. they were sero-discordant. Fifty-eight respondents (14.6%) did not know the HIV status of their spouse.

Of the respondents who were married, in de facto relationships, divorced, widowed or separated, 93 respondents (23.5%) knew that their spouse was currently receiving or had received HAART. One hundred and sixty-one respondents (40.7%) said their spouses were not on therapy and 55 (13.9%) did not know if their spouses were receiving HAART. There was a significant difference between the male and female respondents, with more female respondents not knowing if their spouses were receiving HAART. Of those respondents with a known HIV-infected spouse, 43.5% of the respondents (93/214) knew that their spouses were on ART, 110 respondents (51.4%) knew that their spouses were not on ART, and 8 (3.7%) did not know.

Two hundred and sixty-seven respondents (67.3%) had told their spouse about their HIV-infected status, and there was a significant difference between disclosure among females and males: 76.7% of the male respondents had disclosed their HIV status to their spouses in comparison to 58.7% of the female respondents. Among the respondents who had ever had children, 76 (19.2%) respondents knew that at least one of their children was HIV-positive. Two hundred and twenty-four (56.6%) respondents said that their children were not HIV-infected, and 74 respondents (18.7%) did not know the HIV status of their children. Three hundred and nineteen respondents (67.0%) knew all the routes of transmission of HIV from mother to child, that is, in utero, during delivery and via breast milk but there was no significant difference between males and females 64.7% versus 69.3% respectively.

Table 10: HIV History of PLHIV in Gulu District, Uganda, February-May 2009

	Total		Males		Females		p value*
	n	(%)	n	(%)	n	(%)	
Time of HIV Diagnosis (months) [a]							**0.037**
0-<12	137	(29.1)	77	(32.6)	60	(25.6)	
12-<24	80	(17.0)	44	(18.6)	36	(15.4)	
24-<36	72	(15.3)	36	(15.3)	36	(15.4)	
36-<48	60	(12.8)	32	(13.6)	28	(12.0)	
48 -<60	43	(9.1)	21	(8.9)	22	(9.4)	
60+	78	(16.6)	26	(11.0)	52	(22.2)	
Time of HIV Diagnosis (months) [a]							**0.032**
Less than 24 months	216	(46.0)	121	(51.1)	95	(40.8)	
24 months and more	254	(54.0)	116	(48.9)	138	(59.2)	
Time attending HIV clinic (months) [b]							**0.003**
0-<12	183	(38.6)	105	(44.3)	78	(32.9)	
12-<24	78	(16.5)	37	(15.6)	41	(17.3)	
24-<36	71	(15.0)	40	(16.9)	31	(13.1)	
36-<48	59	(12.4)	27	(11.4)	32	(13.5)	
48 -<60	44	(9.3)	19	(8.0)	25	(10.5)	
60+	39	(8.2)	9	(3.8)	30	(12.7)	
Time attending HIV clinic (months) [b]							0.051
Less than 24 months	261	(55.1)	141	(59.7)	120	(50.4)	
24 months and more	213	(44.9)	95	(40.3)	118	(49.6)	
Pregnant at time of HIV diagnosis			N/A		42	(18.7)	
Respondents on HAART [b]	236	(49.8)	107	(45.1)	129	(54.4)	0.054
Respondents on							

	Total		Males		Females		p value*
	n	(%)	n	(%)	n	(%)	
HAART feeling better	216	(92.7)	104	(97.2)	112	(88.9)	**0.029**
Time on HAART (months)							0.285
0-<12	64	(27.4)	29	(27.4)	35	(27.3)	
12-<24	47	(20.1)	27	(25.5)	20	(15.6)	
24-<36	49	(20.9)	19	(17.9)	30	(23.4)	
36-<48	39	(16.7)	19	(17.9)	20	(15.6)	
48 -<60	21	(9.0)	6	(5.7)	15	(11.7)	
60+	14	(6.0)	6	(5.7)	8	(6.3)	
Time on HAART (months) [c]							0.149
Less than 24 months	112	(47.7)	57	(53.3)	55	(43.0)	
24 months and more	123	(52.3)	50	(46.7)	73	(57.0)	
Spouse's HIV status [d, e]							**< .001**
Positive	213	(53.7)	132	(69.8)	81	(38.9)	
Negative	49	(12.3)	30	(15.9)	19	(9.1)	
Not applicable	77	(19.4)	10	(5.3)	67	(32.2)	
Unknown	58	(14.6)	17	(9.0)	41	(19.7)	
Spouse receiving HAART [e, f]							**< .001**
Yes	93	(23.5)	56	(29.5)	37	(18.0)	
No	161	(40.7)	103	(54.2)	58	(28.2)	
N/A	87	(22.0)	13	(6.8)	74	(35.9)	
Don't know	55	(13.9)	18	(9.5)	37	(18.0)	
Disclosure of HIV status to spouse [d, e]							**< .001**
Yes	267	(67.3)	145	(76.7)	122	(58.7)	
No	61	(15.4)	44	(23.3)	17	(8.2)	
N/A	69	(17.4)	0	(0.0)	69	(33.2)	
Any children HIV-							

	Total		Males		Females		p value*
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	
positive [g]							0.671
Yes	76	(19.2)	32	(16.9)	44	(21.3)	
No	224	(56.6)	108	(57.1)	116	(56.0)	
N/A	22	(5.6)	12	(6.3)	10	(4.8)	
Don't know	74	(18.7)	37	(19.6)	37	(17.9)	
Complete PMTCT knowledge	319	(67.0)	154	(64.7)	165	(69.3)	0.330

HAART, highly active antiretroviral therapy; N/A, not applicable; PMTCT, Prevention of Mother-to-Child Transmission; [a] data for six respondents missing; [b] data for two respondents missing; [c] data for one respondent on HAART missing; [d] data missing for three respondents; [e] single respondents excluded; [f] data for four respondents missing; [g] data for one respondent missing; *p value calculated using Chi-square

5.1.5 Fertility desires of PLHIV living in Gulu District, Northern Uganda

In Section 4 of the questionnaire, both the male and female respondents were asked questions on their fertility preferences. The results are summarised in Table 11. One hundred and eighty-four respondents (42.8%) stated that they would desire more children in the future. There was a significant difference between the male and female respondents with 54.2% of the male respondents desiring to have more children in comparison to 31.7% of the female respondents: Yates' Continuity Correction 21.499, d.f. = 1, $p < .001$. The respondents who said that they wanted more children in the future were asked how soon they wanted to have more children. Of the 184 respondents, 97 (52.4%) said that they would prefer to wait a few years before the next child. The majority of both the male respondents (52.6%) and female respondents (52.2%) said that they would prefer to wait a few years to have more children.

Eighty-seven (42.0%) of the married respondents and those in de facto relationships said that their spouse desired to have more children, 84 respondents (40.6%) said

they did not desire to have more children, but 36 respondents (17.4%) said they did not know if their spouses wanted more children or not. In terms of level of importance for more children among the PLHIV's spouses, there was a significant difference between the male and female respondents. Of the female respondents, 53.7% reported that having children was very important for their spouse, while 42.0% of the male respondents said that having more children was not important to their spouse. Overall, 76 respondents (44.4%) wanted the same number of children as their spouses.

Two hundred and forty-six respondents did not desire to have more children, and of these, 146 respondents (59.3%) were not using any method of contraception to prevent further pregnancies. The majority of these respondents (46.3%) were not using contraception because they were abstinent at the time, while 14.7% were not married. Other reasons included health concerns, fear of side-effects, infrequent sex and opposition to contraception. There was, however, no statistical difference between the male and female respondents.

Table 11: Desire for children among PLHIV in Gulu District, Uganda, February-May 2009

Characteristic	**Total**		**Males**		**Females**		**p value***
	n	(%)	n	(%)	n	(%)	
Do you desire more children in the future? [a]							**< .001**
Desire more children	184	(42.8)	115	(54.2)	69	(31.7)	
Don't desire more	246	(57.2)	97	(45.8)	149	(68.3)	
How soon do you want more children? [b]							0.892
Months	17	(9.2)	10	(8.6)	7	(10.1)	
Years	97	(52.4)	61	(52.6)	36	(52.2)	
Soon	8	(4.3)	6	(5.2)	2	(2.9)	
After marriage	23	(12.4)	14	(12.1)	9	(13.0)	
Other	3	(1.6)	2	(1.7)	1	(1.4)	
Don't know	9	(4.9)	4	(3.4)	5	(7.2)	

Characteristic	Total		Males		Females		p value*
	n	(%)	n	(%)	n	(%)	
Missing	28	(15.1)	19	(16.4)	9	(13.0)	
Does your spouse want any more children? [c, d]							0.121
Yes	87	(42.0)	55	(38.2)	32	(50.8)	
No	84	(40.6)	65	(45.1)	19	(30.2)	
Don't know	36	(17.4)	24	(16.7)	12	(19.0)	
How important is it to your husband/wife to have more children? [c, e]							**0.001**
Very important	51	(30.2)	29	(22.7)	22	(53.7)	
Important	22	(13.0)	21	(16.4)	1	(2.4)	
Somewhat important	2	(1.2)	1	(0.8)	1	(2.4)	
Not important	71	(42.0)	61	(47.7)	10	(24.4)	
Don't know	23	(13.6)	16	(12.5)	7	(17.1)	
Does your husband/wife want the same number of children that you want, or does he/she want more or fewer than you want? [c, f]							**0.004**
Same	76	(44.4)	67	(50.8)	9	(23.1)	
More	24	(14.0)	13	(9.8)	11	(28.2)	
Fewer	8	(4.7)	6	(4.5)	2	(5.1)	
Don't know	63	(36.8)	46	(34.8)	17	(43.6)	
Why are you not using contraception? [g]							0.143
Not married	20	(14.7)	4	(13.3)	16	(15.1)	
Not having sex	63	(46.3)	15	(50.0)	48	(45.3)	
Infrequent sex	2	(1.5)	0	(0.0)	2	(1.9)	
Menopausal	18	(13.2)	1	(3.3)	17	(16.0)	
Sub fecund	5	(3.7)	1	(3.3)	4	(3.8)	
Postpartum	1	(0.7)	0	(0.0)	1	(0.9)	

Characteristic	Total		Males		Females		p value*
	n	(%)	n	(%)	n	(%)	
Breastfeeding	3	(2.2)	0	(0.0)	3	(2.8)	
Respondent opposed	5	(3.7)	3	(10.0)	2	(1.9)	
Wife opposed	1	(0.7)	1	(3.3)	0	(0.0)	
Religion	1	(0.7)	0	(0.0)	1	(0.9)	
Health concerns	5	(3.7)	2	(6.7)	3	(2.8)	
Side effects	5	(3.7)	1	(3.3)	4	(3.8)	
Inconvenient	1	(0.7)	1	(3.3)	0	(0.0)	
Other	7	(5.1)	1	(3.3)	6	(5.7)	

*p value calculated using Chi square; [a] data for 46 respondents missing; [b] calculated for those who desire more children; [c] calculated for respondents in married/de facto relationships; [d] data for 29 respondents missing; [e] data for 67 respondents missing; [f] data for 65 respondents missing; [g] data for nine respondents missing

5.1.6 Factors associated with desire to have children among PLHIV

5.1.6.1 Bivariate analysis

Bivariate analysis was conducted to determine the factors associated with desire to have children among PLHIV in Gulu, Northern Uganda and the results are summarised in Table 12. The factors significantly associated with desire to have children on bivariate analysis at the p<.05 level were age of the respondent, sex, marital status, education, age of the spouse, number of children, history of death of a child, spouse's desire to have children and discussion of family planning with health workers. Desire to have children is also associated with number of months since diagnosis, number of months on HAART and number of months attending the HIV clinic.

The respondents who were aged less than 30 years were seven times more likely to desire to have children than respondents aged 30 years or more [odds ratio (OR) = 7.14, 95% confidence interval (CI): 4.76-11.11]. The male respondents were over twice as likely to desire more children compared to female respondents (OR = 2.56, 95% CI: 1.73-3.79). The respondents who were single were 15.9 times more likely to desire children than those who were married or in de facto relationships (OR = 15.87,

95% CI: 6.58-38.46) and 23.3 times more likely to desire children than those who were divorced or widowed (OR = 23.26, 95% CI: 9.35-58.82). Overall, the single respondents were 18.5 times more likely to desire more children that the other respondents (95% CI: 7.75-43.48). The respondents who had an education were 1.75 times more likely to desire children in the future than those without an education: OR = 1.75, 95% CI: 1.04-2.94. The respondents who had spouses younger than 30 years were 4 times more likely to desire to have children than the respondents older than 30 years of age (OR = 4.55, 95% CI: 2.27-9.09).

The respondents who had never had a child were 14 times more likely to desire a child/more children than the respondents who had ever had children (OR = 14.29, 95% CI: 6.25-33.33). The respondents who had lost a child were less likely to desire to have children in the future (OR = 0.37, 95% CI: 0.24-0.59). The respondents who had not discussed family planning with health workers were two times more likely to desire more children in the future than those who had discussed family planning with their health worker (OR = 2.27, 95% CI: 1.52-3.45). The respondents who had a diagnosis for longer (OR = 0.65, 95% CI: 0.44-0.95), those who had been at the clinic longer (OR = 0.62, 95% CI: 0.42-0.92), and those who had been on ART longer (OR = 0.54, 95% CI: 0.31-0.96) were also less likely to desire more children. Among respondents who were married and in de facto relationships, the respondents whose spouses desired children were more than 100 times more likely to desire children than those respondents whose spouses did not desire to have more children (OR = 111, 95% CI: 25-500).

Table 12: Bivariate analysis of factors associated with desire for children among PLHIV in Gulu District, Uganda, February-May 2009

Characteristic	Total n	Desire to have children n	(%)	OR (95% CI)	p value*
Age group [a]					
15-29 years	180	125	(69.4)	1	
30-49 years	251	59	(23.5)	0.14 (0.09-0.21)	**< .001**
Sex [b]					
Female	218	69	(31.7)	1	
Male	212	115	(54.2)	2.56 (1.73-3.79)	**< .001**
Marital status [a]					
Single	64	58	(90.6)	1	
Married/de facto	220	83	(37.7)	0.06 (0.03-0.15)	**< .001**
Separated/divorced/widowed	147	43	(29.3)	0.04 (0.02-0.11)	**< .001**
Type of marriage (if married or de facto) [c]					
Polygamous	62	24	(38.7)	1	
Monogamous	157	58	(36.9)	0.93 (0.51-1.69)	0.930

Characteristic	Total n	Desire to have children n	(%)	OR (95% CI)	p value*
Residence [b]					
Rural/IDP	225	94	(41.8)	1	
Urban	205	90	(43.9)	1.09 (0.74-1.59)	0.728
Education [b]					
Yes	352	159	(45.2)	1	
No	78	25	(32.1)	0.57 (0.34-0.96)	**0.046**
Religion [d]					
Other	115	53	(46.1)	1	
Catholic	311	128	(41.2)	0.82 (0.53-1.26)	0.422
Spouse's age group (if married or de facto) [e]					
15-29 years	58	35	(60.3)	1	
30-49 years	114	29	(25.4)	0.22 (0.11-0.44)	**< .001**
Number of children [f]					
0 children	62	55	(88.7)	1	
1 child and more	367	129	(35.1)	0.07 (0.03-0.16)	**< .001**

Characteristic	Total n	Desire to have children n	(%)	OR (95% CI)	p value*
History of death of child [d]					
No	299	148	(49.5)	1	
Yes	127	34	(26.8)	0.37 (0.24-0.59)	**< .001**
Current use of family planning [b]					
Yes	172	72	(41.9)	1	
No	258	112	(43.4)	1.06 (0.72-1.57)	0.827
Discussion of family planning with health workers [g]					
No	163	90	(55.2)	1	
Yes	257	91	(35.4)	0.45 (0.29-0.66)	**< .001**
Discussion of family planning with spouse (single respondents excluded) [h]					
Never	124	44	(35.5)	1	
At least once	210	73	(34.8)	0.97 (0.61-1.54)	0.988
Clinic attended [a]					
Lacor (faith-based hospital)	149	61	(40.9)	1	
Others (GNRH and TASO)	282	123	(43.6)	1.12 (0.75-1.67)	0.666

Characteristic	Total n	Desire to have children n	(%)	OR (95% CI)	p value*
On HAART [f]					
Yes	208	84	(40.4)	1	
No	221	99	(44.8)	1.19 (0.82-1.76)	0.409
HIV status of spouse (single respondents excluded) [i]					
Negative	46	17	(37.0)	1	
Positive	199	81	(40.7)	1.17 (0.60-2.27)	0.764
Disclosure of HIV status to spouse (single respondents excluded) [j]					
Yes	245	90	(36.7)	1	
No	56	26	(46.4)	1.49 (0.83-2.68)	0.233
Months since diagnosis [k]					
Less than 24 months	200	97	(48.5)	1	
24 months or more	225	85	(37.8)	0.64 (0.44-0.95)	**0.033**
Months on HAART (only those on HAART) [l]					
Less than 24 months	101	48	(47.5)	1	
24 months or more	106	35	(33.0)	0.54 (0.31-0.96)	**0.047**

Characteristic	Total n	Desire to have children n	(%)	OR (95% CI)	p value*
Months attending HIV clinic [f]					
Less than 24 months	240	114	(47.5)	1	
24 months or more	189	68	(36.0)	0.62 (0.42-0.92)	**0.022**
Complete PMTCT knowledge [a]					
Yes	296	125	(42.2)	1	
No	135	60	(44.4)	1.09 (0.73-1.65)	0.744
Pregnancy status (females only) [m]					
Pregnant	18	4	(22.2)	1	
Not pregnant	195	63	(32.3)	1.67 (0.53-5.28)	0.538
Spouse's desire for children (if married or de facto) [n]					
Yes	82	61	(74.4)	1	
No	78	2	(2.6)	0.009 (0.002-0.040)	**< .001**
Any HIV-positive children(among those with children)[o]					
Yes	72	22	(30.6)	1	
No	209	78	(37.3)	1.35 (0.76-2.40)	0.373

CI, confidence interval; GNRH, Gulu National Referral Hospital; HAART, highly active antiretroviral therapy; IDP, internally displaced person; OR, odds ratio; PMTCT, prevention of mother-to-child transmission; TASO, The AIDS Support Organization; * p

values calculated using Yates Correction for Continuity Chi-Square or Fisher's Exact Test where appropriate; [a] data for 45 respondents missing, [b] data for 46 respondents missing; [c] data for 17 respondents missing; [d] data for 50 respondents missing; [e] data for 64 respondents missing; [f] data for 47 respondents missing; [g] data for 56 respondents missing; [h] data for 66 respondents missing; [i] data for 155 respondents missing; [j] data for 99 respondents missing; [k] data for 51 respondents missing; [l] data for 29 respondents missing; [m] data for 25 respondents missing; [n] data for 10 respondents missing; [o] data for 19 respondents missing

5.1.6.2 Multivariate analysis

The factors that were significantly associated with fertility desire on bivariate analysis at p<.10 level were used in a multivariate logistic model to determine factors significantly associated with desire to have children. The variables included in the model were age of the respondent, sex, marital status, education, age of the spouse, number of children, history of death of a child, discussion of family planning with health workers, spouse's desire to have children, number of months since diagnosis, number of months on HAART and number of months attending the HIV clinic. The factors that remained significantly associated with desire to have children among PLHIV included sex, marital status, and spouse's desire to have children (Table 13). Age of the respondent, number of children, and death of a child no longer remained significantly associated with desire to have children after multivariate analysis was conducted.

The male respondents were 5.89 times more likely to desire children than the female respondents (AOR = 5.89, 95% CI: 2.40-14.44; p < .001). Respondents who were single were 198 times more likely to desire children than those respondents who were married or in de facto relationships, divorced, separated and widowed (AOR = 198.86, 95% CI: 16.81-2353). The respondents whose spouses desired to have children were 84 times (AOR = 84.13, 95% CI: 28.0-252) more likely to desire children compared to those respondents whose spouses did not desire to have children.

Interaction terms were examined and interaction was demonstrated between sex and spousal desire to have children (p = 0.015) (see Table 14).

Table 13: Multivariate logistic regression analysis of factors associated with desire for children among PLHIV in Gulu District, Uganda, February-May 2009

							95% C.I. for Odds Ratio	
Variable	B	S.E.	Wald	d.f.	*p*	Odds Ratio	Lower	Upper
Sex (male)	1.774	.457	15.046	1	< .001	5.892	2.405	14.437
Spouse's desire for children (yes)	4.432	.561	62.366	1	< .001	84.134	28.004	252.768
Marital status (single)	5.293	1.261	17.625	1	< .001	198.864	16.806	2353.129
Constant	-4.293	.618	48.197	1	< .001	.014		

Table 14: Interaction between Spouse's desire for children, marital status and sex variables

Variable	B	S.E.	Wald	d.f.	*p*	Exp(B)
Spouse's desire for children	2.103	.688	9.332	1	.002	8.189
Sex	-.222	.732	.092	1	.762	.801
Sex by Spouse's desire for children	2.131	.875	5.927	1	**.015**	8.423
Constant	-1.928	.624	9.532	1	.002	.145

Variable	B	S.E.	Wald	d.f.	*p*	Exp(B)
Marital Status	4.355	1.179	13.642	1	< .001	77.896
Spouse's desire for children	3.726	.489	57.977	1	< .001	41.498
Marital status by Spouse's desire for children	15.855	14214.736	< .001	1	**.999**	7684403.841
Constant	-2.733	.439	38.670	1	< .001	.065

Variable	B	S.E.	Wald	d.f.	*p*	Exp(B)
Marital Status	2.577	.541	22.657	1	< .001	13.153
Sex	.888	.226	15.488	1	< .001	2.429
Marital status by Sex	1.261	1.159	1.183	1	.277	3.527
Constant	-1.097	.166	43.614	1	< .001	.334

5.2 Qualitative arm of the study

This section presents a summary of the sociodemographic characteristics of the 26 participants from Gulu town, Opit IDP camp and the surrounding villages, together with the major themes drawn from their interviews. The presentation of the themes is enhanced with extracts of those interviews that best highlight the themes. To preserve confidentiality, 26 participants have been identified by a number and an initial from the interviewer's names: so for example N1 is the first interviewee of Nelson Onekalit (NO), one of the interviewers. The other two interviewers were Ilama Charles (IC) and Clementina Abur (CA).

5.2.1 Participants characteristics

Table 15 summarises the sociodemographic characteristics of the 26 participants (further details about the participants can be found in Appendix 24). There were 12 male and 14 female participants. The mean age of the respondents was 35 years, with an age range of 20-42 years. Nineteen of the study participants were married: two were single, two widowed and one separated. All but two participants had children (range 0-7 children), and five participants had lost children in the past. Twenty participants lived in the Gulu Municipality area and six participants lived in Opit sub-county, one of the sub-counties of Gulu District. Only eight participants had some secondary school education. Nineteen participants were Catholic. Nine of the 26 participants, all male, said they would still like to have children in the future. Fifteen participants, 13 of them female and only two male, said they did not want any more children. One male participant was not sure whether he wanted more children.

Most of the participants (16/26) were on HAART. All participants were attending the HIV clinic at St. Mary's Hospital, Lacor and also had links to Comboni Samaritan, a local organisation that supports PLHIV through the provision of counselling, food, education for children and psychosocial support. Most of the participants lived in simple brick houses or mud huts with grass-thatched roofs, as is typical for the population in this area. Some of the participants were peasant farmers eking out a living from the land, but a few others had small businesses that brought in extra money to support the family. Some of the male participants had more than one wife. Some of the participants also had very young children, conceived and born to them

after their diagnosis of HIV. Eight participants had fathered or given birth to children since their HIV diagnosis: five male and three female participants.

Table 15: Summary of sociodemographic characteristics of the 26 PLHIV interviewed in Gulu District, Uganda, February-May 2009

Characteristic	Number
Average age (range)	35 (20-42)
Number of children	
Number of participants with children	24
Number of participants who had lost a child	5
Residence	
Gulu	20
Opit sub-county	6
Marital Status	
Married	19
Single	2
Widowed	2
Separated	1
Unknown	2
Sex	
Male	12
Female	14
Education	
None	3
Some primary education	10
Some secondary education	8
Vocational training	2
Post-secondary education	1
Unknown	2
Occupation	
Peasant farmer	3
Teacher	1
Businessman	3

Characteristic	Number
Other	19
Religion	
Roman Catholic	19
Anglican	6
Unknown	1
On HAART	
Yes	16
No	2
Unknown	8
Desire to have children in the future	
Yes	9
No	15
Not sure	1
Unknown	1
Fathered children/given birth since diagnosis	
Yes	8
No	7
Unknown	11

HAART, highly active antiretroviral therapy

5.2.2 Factors influencing desire to have children among PLHIV in Gulu

Table 16 below summarises the themes of the factors influencing the desire to have children among PLHIV in Gulu. Each of the themes is discussed in detail in the following section and some quotes are provided that best illustrate the themes.

Decision-making regarding fertility

Reassessment of reproductive career

Among the 26 participants, there was generally good knowledge about the transmission of HIV from mother to child. Similar to the quantitative findings, participants knew that they could infect their children during pregnancy, delivery and after child birth, while breastfeeding. Therefore, decision-making around having children in the future for the PLHIV was a complicated process because the

participants knew that there was a possibility of infecting their children. Most participants had reassessed their reproductive career in light of their HIV-infected status, while others had accepted that their reproductive career had to be truncated and were mainly concerned about looking after the children they had.

Most of the male participants (9/12) desired to have more children and almost all the female participants (13/14) did not desire to have any more children. Even among those participants who desired to have more children, there was an acceptance that they could no longer have as many children as they had initially planned, and not as many as their relatives or HIV-negative people could have. I8, a 32 year old male participant from Lacor, had had six children, two of them conceived after he knew his HIV status. He was concerned that he did not have much longer to live and was anxious to prepare his children for when he passed away. He said:

> "What I think now that I am HIV-positive is that I should prepare things that will help them in future, because my life is now very limited, I can die at any time, therefore I should prepare things like livestock, build a house for them, and buying all that is necessary for a home...my plan is that I work hard so that I can rear either pigs, goats or cattle, and I will divide them equally among my children and tell them that is their property they should keep it well and they will benefit from it economically. I will allot something to them all, including even a child in its infancy."

I8 understood that he could not have as many children as he would have liked. While discussing the possibility of having more children in the future, I8 said:

> "I want only six children after I realised that I am infected with HIV, because in the past my mother gave birth to nine children and my grandmother gave birth to twelve children, I thought I would also bear the same number of children as they did (either nine or twelve). But because I realised that I am HIV-positive and today because of development, the population has grown, so there is problem of land to accommodate very many children and for agriculture. That's why I have decided to have only six children...If I were not HIV-positive, I would bear a number of children like my grandparents did because they had ten or nine children."

When asked about having children as an HIV-positive father, N1, a married father of three from Opit, said:

> "It doesn't mean you should continue to deliver because in order to bring up your children well you should space your children not to deliver like chickens or rabbits. This will enable you feed them and send them to school. If you have four children in your whole life, that's good."

When probed further about whether he would like to have more than his four children N1 said,

> N1: Aah [!], I don't have any other plan for any child. I am contented with the number am having if God allow her to be alive. I don't have plans to father another child.
>
> NO: Does it mean it's not important to have another child in your life?
>
> N1: This depends how my life is getting on; but I should have plans to see whether I have the capacity to care for. But I think it's not good to have many children for us who are positive.

N1 also said that it was important for HIV-infected people not to have too many children and used the term 'sustainable' when describing the number that they should have. Therefore, he, among others, seemed to accept that there was now a limit to the number of children PLHIV could have.

I1, a business man and father of seven from Opit, who had two wives who were both also on HAART, was asked whether being HIV-infected had changed his attitude towards having children:

> CI: Do you think that if you were HIV-negative your thoughts [about having children] would be different?
>
> I1: Yeah if I was not HIV-positive my mind would be different, but as I am now HIV-positive I think I should only produce children that I have the ability to take good care of them.

C2, a 30-year old mother of three, who had had one child since her HIV diagnosis, also indicated that if she didn't have HIV, she would have as many children as she wanted:

> "…of course I would behave like other people with normal life and bear as many children as I want."

Table 16: Main themes around the desire to have children among PLHIV in Gulu

Select Codes	Basic themes identified	Organising Themes
No desire to have any more children Can't have as many as want Will now look after the children they have Secretly using contraception	Reassessment of reproductive career	Decision-making
Wives and husbands discussing if and when to have more children	Joint decision-making	
Defer to male Husband over-riding decisions Husband gets drunk and reneges on promise to use condoms	Male dominance in fertility-related decision making	
HIV doesn't change mind about having children If God wishes will have more	Fatalism	

Select Codes	Basic themes identified	Organising Themes
HAART makes healthier and looks for new partner to have children	Effect of HAART on desire	External influences
Wants to have children because PMTCT can protect child from infection	Effect of PMTCT services on desire	
Desire for wife to have own children Family support for more children Clan members expecting more children Relatives objecting to any more children	Spousal and family influences and expectations	
Having children enhances respect from husband Will be deemed an adult if have children Will appear small if don't have children People querying ability to produce	Respect in society	
Positive support from health workers at the clinic	Health workers' influences	
Children inherit home 'Labongo wiya': my own descendants People will remember us when see children	Heirs and inheritance	Cultural influences

Select Codes	Basic themes identified	Organising Themes
Worry that pregnancy will worsen health Worry that bleeding will worsen wife's health	Personal health concerns	Health concerns
Distress at thought of infection of children	Concerns for the children's health and their potential to be infected	
		Stigma*
Pleasure at delivery of newborn child Children bring happiness in home, take away bad thoughts Having children will increase the love Having children will make marriage stronger	Children as blessings Children as sources of joy Children strengthen a marriage Children as future sources of help	PLHIV attitudes to children

*See Chapter 6 for codes and themes under stigma

HAART, highly active antiretroviral therapy; PMTCT, prevention of mother-to-child transmission

As discussed previously, female participants, in particular, did not want to have any more children. N2, a female participant who had already lost two children, said she was no longer interested in having children after she discovered her HIV status and despite the fact that she was on HAART and feeling much better. Another relevant factor was that since her husband died, she had not had another partner or husband and had no desire to have one. When asked whether she wanted more children, she said:

> "Now that am sick, I feel contented with the one I have because if I continue to deliver, time will come when I am not there, their father is also not there. They will have a very difficult life. It's better to care for the one I have now."

N4, another female participant, also had no interest in having any more children. She was a widow and had had five children, two of whom had died. She had started a new relationship but described her current partner as 'useless' because he was not helping her. She described the experience which made her unlikely to have children again:

> "I don't want to deliver because by the time my husband died he left me with a 3 month pregnancy. I carried that baby till delivery, that child was often ill. The child disturbed me. The baby was already positive. I struggled with the child for 4 years, was initiated on ARV [antiretroviral drugs] for one week but died in the second week. This has made me lose interest in having a child."

In fact N4 was so determined not to have more children that she had started herself on Injectaplan, a form of contraception. When asked about whether her husband wanted more children, she said:

> "He wants to have a child but I told him if he wants to have a child then let him look for a woman who can deliver, for me my time has passed."

N4 was not the only female participant whose views on child bearing differed from her husband. N6, a mother of three, said that her HIV status had changed her attitude towards having more children. She did not want to have any more children, but her husband insisted that she should have more children. She had recently conceived but the pregnancy ended in a miscarriage and her husband accused her of deliberately

aborting the baby. She said having the pregnancy was not her idea but her husband's. She felt that any more pregnancies would weaken her and was more concerned about looking after the children she already had. Though she already had a male child, this child did not belong to her current husband and she opined that this could be the reason why her husband insisted she have more children. She had resorted to secretly using contraception because despite many discussions about having children, her husband refused to listen to her. Her husband even threatened that he would get another woman who could give birth:

> N6: I think the three I have is enough because no one will help me take care of them. That's why I am contented with that number.
>
> NO: What does your husband say about having children?
>
> N6: For him he wants more children.
>
> NO: What exactly does he say?
>
> N6: He says wants more children, and he says that if I cannot deliver more children, he has to get someone else who can deliver. [He says] that at least I have to add one or two children.

The above examples illustrate that some of the participants had reassessed their ability to have children and what the burden would be if they had more than they could possibly support. Female participants, more than male participants, particularly wanted to stop having children. Of note is how some men overrode their wives desire and women who were unable to negotiate, had to resort to secretly using contraception, as will be described later. However, not all participants necessarily thought that they should not have children just because they were HIV-positive. I7, a 40-year old father of six, said that he still wanted to have more and said he and his wife would be able to take care of their children:

> "My wife say that as God has put HIV to be there, it should not stop us from having children...It is also important to her because she knows that in case either of us die one of us will remain to take care of the children because we are not all going to die on the same day...I want to get children because I know very well that HIV is not going to kill me in the near future and that will give me time to care for my children until they grow up."

Joint decision-making

Some participants indicated that they discussed future plans to have children with their spouses and that the decision to have children was jointly taken. Most participants did not take these decisions lightly as they worried about infecting their own children. N1 from Opit was asked if having a child was a joint decision between him and his wife. He replied:

> "Yes, we decided together."

Several male participants indicated that their wives agreed to have more children on certain conditions. According to I2, a 32-year old peasant farmer, his wife suggested that the children should be spaced in order to grow up healthy:

> "Yes we sat down and discussed about it and she accepted it, she also said next time we should space the children to see that they grow up in good health."

When asked whether he had discussed having children with his wife, I8, a 32-year old male participant from a village near Lacor hospital, said:

> "We sat down and discussed the issue together...She said as we wanted more children, it should also be the last so that we can plan how to take care of all the children we have."

Therefore some women were able to negotiate with their husbands. This probably depended on the nature of the relationship and whether the women felt empowered enough to determine the number of children they could have.

Male-dominated decision-making

As described, in some cases there was male dominance in fertility-related decision making. I2, a peasant farmer and father of three who had known his HIV status for eight years, desired to have more children and influenced his wife:

> CI: Was it your desire that your wife should bear this child?
>
> I2: It was my desire, but also we talked together about it in order to bear this child.
>
> CI: As you said you discussed it together with her; why was it important to bear a baby from your side?
>
> I2: It is important because I want to have a child as I am still young and I have sexual desire. I should not go and have sexual intercourse elsewhere because I might get other diseases from somewhere, then it is not good.

Sometimes the male domination in decision-making was not so direct. Chapter 7 on contraception use among PLHIV in Gulu discusses the way in which husbands determined whether their wives used contraception or not. Sometimes women who

did not want to have any more children were overridden by their husbands. I4, a 37-year old mother of five, specifically said she was not interested in having any more children. She felt that five children were enough and that having more would weaken her. Though her first four children were HIV-negative, she was not sure of the status of the last child. Her husband refused to use condoms to prevent more pregnancies. She said:

> "We always discuss this with him, but when he is drunk he reneges on what we have agreed together...That why I told you that we can decide on not having any more children, but when he drinks he changes his mind and start demanding for another baby, but his other family members don't like the idea."

C1, a 34-year old mother of one, said she did not want to have any more children, but she relied on her husband to bring condoms:

> "I have never gone for one though I hear about, but we do use condom all the time and it is my husband who bring it. When he has forgotten, we just meet without it."

C2, a mother of a four month old baby conceived after her HIV diagnosis, was unable to use the pill because of severe side effects and was asked whether her husband would allow use of condoms instead. She replied:

> "No, he doesn't allow to use them."

As described in detail in Chapter 7, some women seemed resigned to their fate of lack of control over their own fertility and acquiesced to their husbands' wishes. However, as has been outlined here, others were taking their fertility decisions into their own hands and using contraception without their spouses' knowledge.

Fatalism

Some participants seemed to be fatalistic in their attitudes towards having children and considered that having children was an event that was out of their control. There were comments from some participants that indicated that child bearing was associated with their strong religious and cultural background. I2 said:

> "What I think is this: as we are still young people and also as I know you cannot stop bearing children, but if it reaches a time it is only God who knows if this is possible because we believe in God always."

I7, a father of six, who was interested in having up to eight children, said:

> "I feel I should continue to have more children if God agrees that we be alive on earth."

External influences on desire to have children among PLHIV

There were several external influences that impacted on the participants' desires to have children in the future. The most influential were HAART and PMTCT programs, spousal and family expectations, health workers influences, and the desire to have respect in the community.

Highly active antiretroviral therapy and the desire to have children

HAART had a major influence on some PLHIV's desire to have children in the future and determined whether some of the participants would have children or not. HAART allowed them to contemplate having children in the future because they could now look after the children themselves and had a reduced risk of MTCT. I1, who said that HAART made him feel healthier and able to look after his own children, had two HIV-infected wives both of whom conceived after they were started on HAART. They were able to test their children for HIV and when they found that their children were HIV-negative it was a relief for the family:

> "Yes, before I was put on ARV I decided not to have children because thought that after I die, nobody would take care of them, but with good luck I found that I improved after starting ARV, and I produced two children, and when they were tested for HIV it was found that both of them were HIV-negative and that is because I am taking ARVs properly."

I1 strongly believed in the importance of adherence to HAART in preventing MTCT and said that he knew of HIV-infected people who had gone on to have HIV-infected children:

> "What I think about it is that, if you produce children without adhering to treatment then you should not produce them."

With improvement in their quality of life, HAART made it possible for some PLHIV to look after their children. N1 indicated that HAART made him much stronger and looking after children much easier:

> "Because not like when I was very weak, when I began taking ARV I was much better. No malaria, nothing like illness I was even doing better things than these who

are HIV-negative. This made me think I still have capacity to take care of another child. So I feel I am able to bring up my current child."

N3, a 34-year old male participant from Opit, said that he felt useless and wanted to die when he received his HIV-positive result. For a while he didn't access treatment and was worried about all the side-effects he had been warned about. After accessing HAART, he started to feel stronger. Since his HIV diagnosis, he had had two children, one of whom died. When asked why, considering his status he wanted to have children, he explained that HAART had made them 'healthy', and like a healthy person, he had urges:

> "Because now am living as a healthy person, even from my house, my wife sees me as a healthy man. I also see that she is healthy. Of course our desires come and [we] act as both healthy people."

PMTCT and the desire to have children

The availability of PMTCT programs allowed some PLHIV to reassess their future and contemplate having more children. Some PLHIV had had HIV-infected children in the past and hoped that access to PMTCT would ensure that they gave birth to HIV-negative children. I6, a 32-year old shopkeeper from Laliya, a village a few kilometres from Gulu town, was one of the first beneficiaries of the Lacor PEPFAR-supported HAART project. He had two HIV-infected children and regretted that his children were infected before he and his wife knew their HIV status. The availability of PMTCT allowed them to have an HIV-negative child:

> "After realising that I was HIV-positive I took my wife and the two children for HIV test and found that I, my wife and all my two children were infected with HIV and that made us to think that the two children got infected because we did not know our status. We can do something to prevent mother to child transmission of HIV and it is possible for us to have another child who will be HIV-negative that's why we got the last child."

When probed further about why they wanted to have another child despite having two HIV-infected children, this male participant said:

> I6: We desired to have the child because we have two children who are HIV-positive and we learnt later that HIV-positive people can bear children who are HIV-negative if they get PMTCT care, and we if prayed it God can give us a HIV-negative child then it would be good.

CI: You told me that the child was tested and found to be HIV-negative?

I6: Yes the child is HIV-negative.

Therefore some of the participants had a good understanding of MTCT and appreciated the role of HIV-infected people and the health system in the prevention of HIV transmission to children. They understood that PLHIV had to be proactive in seeking treatment and advice from health workers in order to achieve good outcomes for their infants. But the participants also did not want health workers to judge them or compel them to stop having children. I6 had this to say:

> "Regarding people living positively with HIV/AIDS some of them wants to have children, I would say that a person can still bear a child even if they are HIV-positive, but you should only do so in consultation with the health worker, so if you want a child you should talk to your doctor or counsellor as to get the relevant information about how to care for the baby right from conception until birth, and even after birth, preventative measure should be taken because the baby can still be infected even after birth, so the baby should be care for even after birth, so that it lives for a long time in good health without being infected with HIV. And this can only be possible if you do so in agreement with your partner, and the health worker because they play a major role in everything, but if you decide yourself only then the child might become infected with HIV. That should be the decision of people living with HIV and they should not be forced or it should not be imposed upon them, even you should not impose this decision on your wife and your wife should not impose her decision on you and even the health worker should not impose his decision on you, therefore every party involved should have the good will and it will be successful."

Similarly, I8 said:

> "For the child we agreed together to have the child, because the health workers informed us that even if you are HIV-positive you can bear a HIV-negative child and we do so and found that the child is HIV-negative."

I10, a 35-year old male respondent from Alokolum, 10 kilometres from Gulu town, also explained that he had had three children with his first wife who had since died of AIDS. He had recently met a new woman with whom he was planning to have another child. The whole family was aware that they both are HIV-positive and he

had had several discussions with them and his doctor about having children in the future. He was anxious to have a child with his new wife and felt positive about having an HIV-negative child in light of the availability of the PMTCT program. He said:

> "I know that I am HIV-positive but I want to get a child at least with the woman that I have now, because with the virus, even if you are HIV-positive, if you follow what is required, when you are pregnant, and you use PMTCT drugs as a means of preventing the child from getting HIV, the child will also survive and live."

N3, like some of the other male participants, escorted his wife to antenatal care to support her during her pregnancy and to ensure she received treatment. He said:

> "… When I learn that my wife had conceived especially the latest pregnancy, I took her to Lacor Hospital. By that time she already had open her file in Lacor, she was booked in antenatal from Lacor. I was present in antenatal. She was initiated on ART when she was 5 months pregnant. I encouraged her to take her drugs giving example on my past experience. She delivered from Lacor caesarean section. The baby was given NVP syrup, combined with infant milk."

What is apparent is that most of the participants were well engaged with the health services and accessing HAART and PMTCT services. They had a high level of knowledge and understanding around their illness and its impact on several aspects of their life, including their ability to reproduce. However they wanted to be able to make choices and this is what HAART and PMTCT enabled them to do.

Spousal and family influences and expectations

As described earlier, a number of female participants were under pressure from their spouses to have more children despite their own wishes to the contrary. Similarly, some male participants also indicated that they needed to meet the expectations of their wives. Though I10 and N1 already had children with other women, it was important for them to meet their current spouse's need to have children of their own. They considered this to be a way of strengthening the relationship. Step-children would not be considered of the same lineage, so each woman would want to have her own to prove her own worth. I10 said:

> "… I am thinking that, if possible, this new woman, I should not live with her without getting a child at least a child should be there."

N1 had already had children with another woman but he said of his current wife:

> "The first wife I had left me with two children. The current one was requesting me if I could also have a child with her, since she has never had a child in her life. My doctor talked to both of us and as I talk now, my wife has a baby. When my wife was pregnant I was very happy because I thought I would not get any other child again."

Similarly N3, a father of four children, none of whom were born to his present wife, said:

> "Because the children I father, some alive, some are dead. Even at home, am the first born to my father. I have four children two are with me, two are outside (with their mother) that is why I want to have children when will stay with me and to give chance for my current wife to have children also. Although she will be taking care of my children what's are not hers. She should also have her true own children. This will give her the courage to take care of all children."

I5 also said that people would mock and query their inability to have children and this would lead to the wife deserting him:

> "To my wife the issue is even more important because if you don't have children with a woman she will not agree to live with you...The reason why I want to have a child is if you have a woman and don't bear children with her your relationship will not be strong or good. Even other people will be insulting her that you are living with him without having a child maybe he is barren that's why you are not having a child with him."

For some of the participants, family expectations to have children were high, despite the fact that they were known to have HIV. When asked about his family's view of them having children considering their HIV status, I10 said:

> "They have no objection because they are the one who suggested that I get a child at least and the women that I have now."

When asked about his family's reaction to him bearing children, considering his known HIV-infected status I2, a male participant, said:

> "Ha [!] My mother wants me to have my children and when we bear the children we should also know how to care for them. But we must not have many children like

> people of the past who would give birth to twelve or twenty children and for us people who are HIV-positive. We should not bear many children so that we are also healthy."

The interviewer noted that from I2's demeanour and tone, it was apparent that he was expected to have children though he was not expected to have as many as 'normal' people would have. This could be because family members did not expect HIV-infected people to live very long or be able to adequately look after a large number of children. When explaining the importance of having children to family members, I6, a 32-year old shopkeeper from Laliya said:

> "To my clan and relatives it was very important to them because they know that as I am HIV-positive at least I should bear a child so that if I die they will see the child and it will be in my memory to them."

N6, a married mother of three children, complained that her relatives thought that three children were not enough and she should have more:

> "They [the relatives] say I should deliver, that 3 children are not enough, that those are few. But they say so because they have not been health educated."

In contrast, other participants' families did not expect them to have too many children, but only the number that they could support. N1 indicated that a few people questioned the fact that he continued to have children after being diagnosed with HIV. Relatives of I8 verbalised their disapproval of his wife getting pregnant. When asked about any objections to his wife's pregnancy, I8 said:

> "Yes those who objected were very many...Some were my aunt, some were my cousins, some were my uncles."

In Uganda, because of lack of a welfare system and minimal support from government, AIDS orphans are looked after by already poor and overburdened extended family members. Therefore relatives were particularly concerned that if the PLHIV had HIV-positive children, then they would be 'creating problems':

> "They feel that if I can bear children who are HIV-negative then I should continue having children, but if they are HIV-positive than I am creating problems, but as they have witnessed that had two HIV-negative children, I may still continue if God wishes so, because it is God that gives the children to you."

I10 said that some relatives were worried that the PMTCT drugs may not be effective in the prevention of HIV transmission to their children and thus create more burdens for them:

> "Others were saying I might give birth to the child and the PMTCT drug would not be effective and that means I have produced a HIV-positive child which would add problems."

In the context of high levels of poverty, family members were concerned that they would be forced to look after the children of PLHIV after they had died.

Respect in the society

Having children is an important part of adulthood in this region and a number of participants indicated that having children guaranteed them respect from other family and community members. It also proved that they were not infertile, a state which was equated by one participant to being 'useless'. N1 said that having children guaranteed them respect in their society:

> "Fatherhood is good also because if since your childhood you never had a child here in our clan, elders see you as a child, they may think because you may be impotent. So if you have a child you are respected because you are now an adult and that gives you respect."

C2, a female participant and mother of three children, one of whom had died, also emphasised the importance of children in enhancing respect from spouses and family and strengthening the relationships between husband and wife:

> "It creates strong relationship between you and the man and stronger love. Children makes home lively, you also feel proud when you called parents...I feel it is good to have a child, you know, children are flowers of the home."

She further emphasised:

> "You will appear small among people and not an important person…without a child the husband will not respect you especially among our society."

And though C2 had experienced hostility from community members because she had a child despite her HIV-infected status, she said:

> "I feel it is necessary for me or anybody who is HIV-positive to have children also it proves that you are not useless completely."

N3, a 34-year old male participant, also said that having children earned a person respect in the community. When asked to explain he said:

> "That respect brought to you by your children or because someone may have your child and say 'Oh I really love this child' these are the benefits. Even at home you feel (at ours) because if you don't have children it's not easy to stay alone in a home. You will see other people's children and there gives you a lot of thoughts, so if God has given you the opportunity it's good but if not then it's bad."

C8, a mother of six children, said:

"It is great being a mother of children, you feel honoured in front of people. You don't feel ashamed in a house of a man, you feel proud of yourself – people respect you so much."

C5, a 38-year old female participant, said:

> "It is very great having children. Without children you are not called a woman."

Health workers' influences

Many of the participants indicated that their decision to have children was influenced by whether the health workers were positive and supportive towards them, and were willing to collaborate towards strategies that would reduce infection of their children. Some women told their husbands that there had to be a consultation with the health workers before they started having more children. This was to enhance positive outcomes for their children and also to get the health workers' approval and support for their decision. As these patients were known to be HIV-positive, it was also important to avoid future backlash. N1 was asked how his HIV-infected wife was received in hospital:

> "When I went to the hospital, when the health workers learnt that my wife was pregnant, some were using very abusive language but some were good to us – some were saying; we are always told about delivery, but we don't listen, we are delivering like pigs. So how can they get time to help us yet we are told not to deliver. Some were good, telling us to follow/ take our medications properly. Some were saying HIV-positive persons should not conceive."

Unlike N1, other participants such as I2 said that they were received warmly by health workers when they went to participate in PMTCT services:

"They welcomed us very warmly when they saw that I accompanied her for ANC...No there was no difficulties which I experience at all because they served me eagerly, you know there are some men who are reluctant to accompany their wives to the hospital if their wife ask them and this is very challenging to the health workers."

Cultural influences

Heirs and inheritance

Among the male participants, kinship and inheritance were particularly important issues. One of the participants, I1, a 37-year old successful business man in Opit IDP camp, used the term 'labongo wiya' - literally translated means 'without my head' - to try to explain that he did not want to die without leaving someone behind to inherit his property and name. This father of seven children and husband to two wives had previously been very ill and had expected to die of his illness. However, after four years on HAART, he had recovered well and was happy about his future prospects. CI, the interviewer, asked the participant about why children were important to him:

CI: What do you think about giving birth to a child?

I1: My idea about having children is that I should also have my descendents.

CI: Are children important in your life?

I1: Yes children are important.

CI: Can you let me know why children are very important in your life?

I1: The reason why they are very important to me is that when I die, people will remember me through the children and they will say this is the children of the late so and so.

CI: Are the children also important to the other people in your home?

I1: The children are very important to us all.

CI: To everybody at home and in your clan?

I1: To all even my clan loves them.

In his notes, the interviewer wrote his impression of the participant's demeanour at this point in the interview:

"The client answered this question with pride, his head raised up and the expression on his face was that of a man who thinks he was doing what was expected of him."

Thus, it was important to individual PLHIV, as well as their close blood relatives, that PLHIV also have children of their own to carry on their name and inherit their property and lands.

N1, a married father of three whose wife was also on HAART, said:

> "At times you may be very sick and die, there are other things (properties) you can leave for your children to inherit."

Similarly, when asked about the importance of children, I6 of Laliya, a village near Gulu town, and father of three, said:

> "In future if you die and you have children then they will be the one to inherit your properties…..What I find the most important thing for children is if you have a home you should bear children, because children are the future of that home, because they will inherit your home."

When asked about the importance of having one's own children, I7, a father of six HIV-negative children said:

> "It is important because they are my descendants, even if I die."

I5 also said that children were important because they were the future:

> "The important thing about children is that they are our future, because if you have a child even after you die people will remember you through your child, but if you die without having a child people will not remember about you at all."

Health concerns

Personal health concerns

Several PLHIV were concerned about their health and in particular what pregnancies might do to further deteriorate their health status. I2 said of his wife:

> "I think it will, especially my wife because the bleeding during child birth makes her lose precious blood which is not good for her health."

I7, a male participant, was also worried that the loss of blood during delivery would make his wife weaker. He said:

> "I think it will affect our health especially the health of my wife, because during child birth she loses a lot of blood, and that's one of the reasons why we want to stop having more children."

C2, C5, C6, C8, N4, N6 and I4, all female participants, were also concerned that future pregnancies would worsen their health status. N6 said that her husband was not particularly concerned about his own health, but she felt it was more important to be healthy and look after one's children. She said:

> "I feel that it's not very important to deliver if you are sick because you can deliver a positive baby and it does weaken you."

When asked whether she still wanted to have more children, C6 said:

> "…but not now because of the disease I have; it will be a double burden to me…it always is scaring situation to me. I feel it is very risky."

Concerns for the children's future, health and their potential infection

Participants did not take their decision to have children lightly. Some participants were concerned that their children could be infected and found ways to reduce this possibility. When asked how he felt about his HIV-infected wife being pregnant and the possibility of the child being infected with HIV, I2, a 32-year old farmer, said that he took his wife to antenatal care to attend the PMTCT program, but would also institute other measures to reduce the risk of transmission of HIV to their infant:

> "My thought was that if the baby is born immediately it should be given cow's milk as supplementary feeding so that it doesn't get the virus; in addition to that I also took her to the hospital for ANC so as to prevent mother to child transmission of HIV."

C2, a female participant who conceived after she knew she was infected with HIV, said that she had a lot of thoughts going through her mind during her pregnancy. She said that her pregnancy went well and the nurses treated her well throughout her pregnancy, but she said that her delivery was difficult. Abandoned by the nurses at the last moment just before she gave birth, she said she pushed her child without assistance onto the floor and there was nobody to cut the umbilical cord immediately. She said:

> "You see, when I was ready to push the baby, they told me I was not ready and they left me alone and I pushed my baby alone on the floor and of course there was no body to cut the cord and so on...the delay in separation of the baby for the mother, there is here I think, if my baby will test positive then the infection could have taken place."

C2 was particularly worried that her child could have been infected at the time of delivery and she was waiting anxiously for the time she would have to test her child and find out its HIV status. She was adamant that she would now wait for at least five years before she had another baby and only if this present child was found to be HIV-negative.

Some participants were also worried about what would happen to their children and who would look after them. N6 said that when she initially received her HIV diagnosis, she was frightened because she did not know who would look after her children:

> "I was not happy, I thought I would die and no one would take care of my children."

I1 was particularly worried about what the children might face in the future when they passed on:

> "Sometimes when you deliver many, yet there are some people who even hate you, so when you die and these children are left in their hands, they mistreat them, saying they are positive, that's why it's good to have a sustainable number."

Similarly, I5, a father of two healthy children, was worried about his children's future:

> "I only worry how they are going to be left after I die because with this disease you will not live for long."

Stigma and fertility desire

Chapter 6 discusses in detail the relationship between stigma and the desire to have children among the HIV-infected respondents in Gulu. Specifically, the second manuscript in Chapter 6 describes the 'Conceptual Model of HIV/AIDS Stigma' used to explore several elements of the stigma process, such as stigma triggers, stigmatising behaviours and agents of stigmatisation (families, communities and health systems) that either directly or indirectly enhanced or reduced desire to have children among the participants. The chapter explains how PLHIV who had experienced stigma were less likely to desire to have children while those who did not experience overt stigma generally continued to desire and have children and showed willingness to cooperate with the health system to achieve better health outcomes through adopting strategies for reducing MTCT.

PLHIV attitudes to children

Most participants spoke positively of children and how they were sources of happiness and joy, and blessings. Other participants thought more of the utilitarian function of children and how they would be a help in the future, especially as they grew older or ailed. Table 17 briefly summarises the value of children by sex. Of note is that the female participants mainly said that children strengthened marriages and bring respect and never mentioned descendants. In a strongly patriarchal society such as this, men would be more concerned about their descendants while women would be more concerned about having strong marriages. Being able to have children ensured that their marriages were strong.

Children as blessings

Some of the PLHIV had positive attitudes towards having children and even considered them blessings. When asked what he thought about HIV-infected women getting pregnant, I8, a 32-year old participant who resided near Lacor Hospital, said:

> "My thought is, I was advising them that it was a blessing that they conceived, so it is very important that they should be close to the hospital to get the necessary care, and it will increase the chances for you to bear a HIV-negative child, and the child will grow up to be your descendant if by any bad luck you die."

C4, a widow and mother of five children, said this of children:

> "Children are gifts of God, it should be always welcome in a family, they bind the husband and wife in their marriage, and children replace you when you leave this world."

Table 17: Value of children by sex

Value of children	Female	Male
Child as memory of parents	3	1
Children are blessings gifts	1	0
Children as descendants	0	4
Children as source of happiness	1	0
Children bring respect	3	1
Children cement marriage	4	0

Children as cementers of marriages

In this highly polygamous society many women are concerned that their husbands will take on other wives. If one is able to have children, then it reduces the reasons for why one's husband would have to take on another wife. So having children 'strengthened' marriage and increased the love between husband and wife. As described earlier, C2 said that children were important because they strengthened a marriage and increased the love between a man and his wife. Similarly C3, a 20-year old female participant, also emphasised the importance of children to a marriage:

> "I think in marriage it means a lot to have children, because it makes a happy marriage, increase love among the two people."

Children as sources of joy

Most participants were pleased that they could have children and were particularly happy when they had HIV-negative children. N1, who was described earlier, said of his wife when asked about how she felt about her pregnancy and having a new baby:

> N1: When my wife learnt that she was pregnant and now that she has a baby, she is very happy because she thought she would not have a baby.
>
> NO: Why was she happy about this child?
>
> N1: Because the child is healthy, she's even not weak, no any other illness, she was very happy.
>
> NO: Have you tested your baby? If so, what were the results?
>
> N1: No, we've not yet test the child, but we are planning because she's till only one month now coming two months. We want to test her at 2 months.

N6, one of the female participants described her marriage as difficult but said this of her children:

> "Because when you are seated lonely and thinking, your children come, talk to you and this makes you happy."

Children as future sources of help

For several participants, children were also seen as a source of help, especially for the parents as they approached their old age or early death, depending on which came first. The children's utilitarian function was represented in ways such as "send him/her to bring you water", "help you if they grow up" and so on. When he was asked about fatherhood and how important it was to him, N1, a male participant from Opit, said:

> "Being a father of children is good because at the time when you are weak and children are there, sometimes you can send him/her to bring you drinking water."

Similarly, I2 said about his children:

> "It is important to bear children because if you bear them and they are negative, they will help you if they grow up."

C2 said:

> "...Because children help a lot in the family, the workload is shared and makes a person feel responsible."

N4, a widow and mother of five, encapsulated the utilitarian function of children when she said:

> "If they grow up they will also help you when you are now helpless. They will take you to hospital if you are very sick, dig for you, feed you and give you other help."

Children as memory of parents

N6, a mother of three, also said children were a source of happiness and also served as memory of their parents:

> "If you have children, in the future if you die, they will be shown during your burial 'there are the children of so and so'. This is good because at least you would have left somebody behind."

5.4 Summary of the Chapter

This chapter presented the social demographics, reproductive and HIV knowledge, and HIV history of the 476 respondents. It summarised the characteristics of the 26 participants who were interviewed, and presented the findings pertaining to the desire to have children among PLHIV in Gulu. The next chapter contains the findings of the relationship between stigma and the desire to have children among PLHIV.

CHAPTER 6: HIV-RELATED STIGMA AND DESIRE TO HAVE CHILDREN AMONG PLHIV IN NORTHERN UGANDA

6.0 Introduction to the Chapter

From the review of the literature, HIV-related stigma was one of the key factors that influenced the desire to have children among PLHIV. Hence, this chapter is dedicated to exploring stigma in detail and its relationship with desire to have children among PLHIV in Northern Uganda. In the first section of this chapter, the concept of stigma is defined, conceptual frameworks are compared, the types and outcomes of stigma elucidated and its impact on health-seeking behaviour explained. HIV-related stigma in Sub-Saharan Africa, Uganda and Northern Uganda are described in detail in order to provide context to the stigma experienced by the PLHIV in Gulu District.

This chapter also includes a peer-reviewed journal article entitled: **Factors associated with perceived stigma among people living with HIV/AIDS in post-conflict Northern Uganda** (Nattabi, Li, Thompson, Orach, & Earnest, 2011a) which quantified the burden of stigma among the 476 respondents and determined its relationship with sociodemographic characteristics, HIV history, HAART use and the desire to have children. This chapter also includes a manuscript entitled: **Between a rock and a hard place: Stigma and the desire to have children among people living with HIV in Northern Uganda** (Nattabi, Li, Thompson, Orach, & Earnest, under review-a) which has been submitted to *Journal of International AIDS Society*. This paper explored the HIV-related stigma experiences of 26 participants, together with the impact of stigma on the desire to have children among PLHIV.

6.1 Stigma

6.1.1 Definition of stigma

Erving Goffman (1963), one of the most recognised authors of stigma literature, defined stigma as a 'discrediting attribute', constituting a "discrepancy between [a

person's] *virtual* and *actual* social identity" (p.3). He explained that in everyday interactions, individuals make assumptions about other people and what sort of characteristics they have. Each person is thus conferred an 'identity', that is, a set of personal and structural attributes and Goffman (1963) called this a 'virtual' identity, because the person is not proven to have these assumed attributes. This is in contrast to the person's 'actual' identity, that is, the set of attributes that the person is found to have on further interaction. According to Goffman, if there is an anomaly between the two identities and one identity is less desirable than the other, the person is reduced in other's minds, from "whole, normal and usual" to "tainted and discredited" and the person possesses a stigma. If the person is found to have a more desirable set of attributes, he/she is 'reclassified' to a higher position, and does not possess a stigma (Goffman, 1963).

Goffman (1963) described three types of stigma: those related to the physical body, those related to the character of a person and those that he termed 'tribal stigma'. 'Physical stigma' was a result of having a physical deformity or an illness such as leprosy or tuberculosis, while 'character stigma' occurred when a person was deemed immoral, e.g. homosexuals, prisoners and drug addicts. 'Tribal stigma' was a consequence of a person belonging to a particular race, religion, tribe or country. Goffman (1963) described this stigma as "transmissible through lineages" and one that contaminated all members of that group, whether by family, race or religious affiliation.

Goffman (1963) further emphasised that an attribute is not in itself stigmatising, but rather the relationship between that attribute and a stereotype. As described in the next section, Link and Phelan (2001) concurred with Goffman and maintained that the attribute, or the 'mark' that is visible, has to link that person to a set of 'undesirable' characteristics in order for that person to possess a stigma. Stigma thus occurs when there is social interaction between those who have the stigmatising attribute and those who do not have it; what Goffman (1963) called the "mixed contact". In ordinary social interactions, where an individual would otherwise be normally received, the undesirable attribute such as an HIV-positive diagnosis or physical deformity 'intrudes' and causes the 'normal' to turn away from the person possessing the stigma.

Dovidio, Major and Crocker (2000) maintained that stigma is a social construction because what may be undesirable in one society may be acceptable in another society, and what may be stigmatising at a particular time, in a particular situation, circumstance or society may not be stigmatising in another time, situation, circumstance or society respectively. Therefore, for example, the historical and social nature of stigma has been illustrated by the waning stigmatisation of homosexual men in many developed countries, and the waning of stigma towards HIV-infected people in many parts of the world. Thus the social and cultural context influences the stigmatising process and determines whether an attribute will be stigmatised at all (Dovidio, et al., 2000).

Since Goffman's seminal work, several authors have defined stigma in various ways. Alonzo and Reynolds (1995) defined the stigmatised as a "category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanising benefit of free and unfettered social intercourse" (p. 340). Similarly, Herek (2002) defined stigma "…as an enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently discredits and disadvantages an individual" (p. 595). Bunn, Solomon and Forehand (2007) defined stigma as a process by which individuals are discriminated against and face prejudice because of known physical, behavioural or medical attributes. These expanded definitions were based on Goffman's conceptualisation of stigma as they related to the individual and identity, how individuals were perceived by themselves and others, and how individuals were treated because of their presumed identity.

Other authors such as Link and Phelan (2001) and Weiss, Ramakrishna, and Somma (2006) argued that this approach to stigma was too narrow, and based on the individual. These authors maintained that stigma must be understood, defined, and conceptualised more broadly. Weiss et al. (2006) argued that Goffman's definition focused on social interactions without due consideration of the structural influences on these interactions. They argued that the interactions could not be divorced from broader social and cultural influences on the behaviour of the stigmatisers and stigmatised groups. Similarly, Reeders (2009a) argued that Goffman's definition

focused the causes of stigma on the bearer of the 'attribute' and led to blame or social judgment of the stigmatised individual, instead of on the social processes that create and perpetuate stigmatisation of particular groups.

6.1.2 Conceptual frameworks of stigma

Conceptually, Link and Phelan (2001) expounded on Goffman's assertion that stigma is a result of a link between an attribute and a negative stereotype. They maintained that stigma exists at a confluence of five distinct but interconnected components including labelling, stereotyping, separation, status loss and discrimination, and power. Link and Phelan (2001) argued that differences between people are omnipresent but there are only some differences that societies select as socially important. They argued that what people select as important changes over time and this also depends on location. For example, differences in eye colour are not considered important in comparison to differences in sexuality (Link & Phelan, 2001). Because these differences are socially selected for importance over others, Link and Phelan (2001) preferred to refer to stigma as a 'label' rather than as an 'attribute', 'condition', or 'mark'. This is because people determine what should be labelled and affix these labels onto others. Of note is that these labels or designations are usually pervasive and are not challenged or questioned (Link & Phelan, 2001).

In order for stigma to occur, the socially-determined label must be linked to a set of undesirable characteristics (Link & Phelan, 2001) and this is referred to as stereotyping. Over time, this link of labels with undesirable characteristics becomes automatic and preconscious (Link & Phelan, 2001). Labelling leads to separation of 'us' from 'them'; or rather, a separation of those who would consider themselves 'normal' from those deemed to be 'abnormal' (Goffman, 1963). Reeders (2009b) argued that this 'separation' serves an unfortunate purpose, especially in the field of HIV prevention because it relinquishes the responsibility of HIV prevention to people infected with HIV or those in the 'risk groups'. Therefore, people who think they are not at risk of contracting the illness may not actively practice prevention methods e.g. condom use. The blame of contracting illness is placed on those deemed to be 'deviant' and people who do not think they are 'deviant' distance themselves from the illness and view themselves as immune from contracting it (Deacon, 2006).

Another component of Link and Phelan's (2001) stigma process is the loss of status and discrimination among people who are stigmatised. They argued that all people who are labelled, stereotyped, set apart and linked to undesirable characteristics, experience status loss and face individual and/or structural discrimination. The person's lower status then becomes a basis for further discrimination. This component of Link and Phelan's conceptual framework should be re-conceptualised as "actual or potential status loss and discrimination", because not all people thought to be 'deviants' experience status loss and discrimination (Dovidio, et al., 2000). People who anticipate stigmatisation or face internal stigmatisation do not necessarily face immediate status loss or discrimination (Herek, 2002) and though status loss is projected onto the 'deviant', it may or may not result in disadvantage to them (Deacon, 2006). In fact, people who are stigmatised may instead have high self-esteem and high levels of resilience (Dovidio, et al., 2000).

Several authors have suggested that stigma should be analytically separated from discrimination (Deacon, 2006; Herek, 2002) and prejudice (Herek, 2002), because overt acts of discrimination do not have to occur for the negative effects of stigmatisation to be felt. Herek (2002) defined discrimination as a behaviour or an action that leads to differential treatment of a group of people based on their attributes. He argued that discrimination is only a manifestation of stigma if the whole society condones it. He further defined prejudice as a negative attitude toward members of a social group and claimed that prejudice becomes stigma only if it is a reflection of the whole society's attitudes towards members of a particular social group. Thus Herek (2002) separated these two concepts from stigma.

In the final component of Link and Phelan's framework, stigma is dependent on power differences between the stigmatised and stigmatisers. They argued that for stigma to exist, there must be differences in social, economic and political power between the two groups. This allows the dominant and powerful group to prevail over the marginalised group and the dominant group's beliefs, attitudes and behaviours to lead to negative and discriminatory consequences for the stigmatised. Similarly, Parker and Aggleton (2003) suggested that stigma should be understood in relation to broader notions of power and domination. They argued that stigma should

be regarded as social and cultural phenomena involving whole groups of people and communities, as well as a process linked to competition for power and entrenchment of social hierarchy and inequality.

Therefore, according to Link and Phelan (2001) and Parker and Aggleton (2003), stigmatisation of HIV-infected people, especially in countries where HIV/AIDS mainly affected traditionally marginalised groups such as women, homosexual men, and/or ethnic minorities, was just another reinforcement of the power differences that already existed. In fact Reeders (2009b) suggested that HIV-related stigma was a form of 'social quarantine', which used social judgment, blame and shame to regulate PLHIV behaviour. Not all authors agree with the domination of powerful groups over marginalised groups as a component of stigmatisation. Deacon (2006) argued that people at different levels of society could participate in stigmatising of PLHIV, not necessarily only those from dominant sectors of the society. In Zambia, stigma also affected high-status members of society who contracted HIV, who were also blamed for contracting the disease (Bond et al., 2003). Thus, power is not necessarily a component of HIV-related stigmatisation.

6.1.3 Types of stigma

In the literature, authors have defined several forms of stigma including received stigma, associated stigma, internalised stigma, anticipated stigma, instrumental stigma and symbolic stigma. Holzemer et al. (2007) defined received stigma as behaviours targeted towards stigmatised groups as experienced by them or explained by others and included neglecting, avoiding and abusing. Received stigma related to the actual experiences of prejudice, stereotyping and exclusion as described by the affected individual, and included overt and more subtle expressions of stigma (Bunn, et al., 2007). Stigmatised PLHIV in five different African countries described a range of experiences that they faced, which included verbal abuse, physical abuse and neglect (Dlamini et al., 2007). PLHIV were usually taunted with stigmatising words that described their physical status or were related to death: phrases like 'moving skeleton' and 'walking corpse' (Nyblade et al., 2003). Other forms of social exclusion experienced by PLHIV in Africa included exclusion from family and community events (Nyblade, et al., 2003).

Associated stigma, also referred to as 'courtesy stigma' (Goffman, 1963) or secondary stigma (Nyblade, et al., 2003), occurred when a person was stigmatised because of a relationship or association they had with the person who was stigmatised (Holzemer, Uys, Makoae, et al., 2007). Goffman (1963) described associated stigma as a consequence of being related through the social structure to a stigmatised individual; a relationship that led wider society to treat both individuals as 'one'. People affected by 'courtesy stigma' included spouses, children, close friends, other family members as well as professional staff such as health workers and volunteers who worked with the stigmatised group (Nyblade, et al., 2003). Usually people may react in two ways to reduce this form of stigma: some may break off the relationship or some may become co-conspirators in hiding the stigmatising attributes. In a study of stigma in Nigeria, spouses of PLHIV assisted in hiding the status of their partners (Smith & Mbakwem, 2010) as a mechanism to prevent further prejudice or discrimination against themselves or their loved ones (Herek, 2002).

Internalised stigma, also referred to as negative self-perception (Holzemer, Uys, Makoae, et al., 2007), is defined as the negative thoughts and behaviours stemming from the presence of a stigmatising condition. Among PLHIV, internalisation of stigma resulted from internal adaptation of negative cultural views that portrayed HIV-infected persons as dirty, deadly or deficient (Sandelowski, Lambe, & Barroso, 2004). Similar to internalised stigma, felt stigma is another term that described an internal sense of shame felt by stigmatised people (Herek, 2002). Some stigmatised people believed that they were 'deviant' and deserving of their stigmatising condition, and this resulted in self-hatred, and shame (Alonzo & Reynolds, 1995). This form of stigmatisation can occur even in the absence of overt forms of stigmatisation.

'Anticipated stigma' has been extensively examined in relation to mental illness (Link & Phelan, 2001) and is the degree to which people expect that they will experience prejudice and discrimination from others in the future because of their condition (Earnshaw & Chaudoir, 2009). When individuals test for HIV for the first time, they fear the future because of the potential loss of identity that could result due to stereotyping (Alonzo & Reynolds, 1995). This form of stigma has various

detrimental consequences; for example among PLHIV it may lead to delayed access to care, and delayed access to PMTCT programs (Kipp, Bajenja, Karamagi, & Tindyebwa, 2007). When people expect or fear rejection or discrimination based on societal determination of stereotypes, they avoid interactions with potential stigmatisers (Link & Phelan, 2001) and restrict their networks to those with similar attributes (Goffman, 1963).

Other types of stigma include 'instrumental stigma' and 'symbolic stigma' (Herek, 2002). Instrumental stigma refers to the type of stigma incurred because the condition is lethal and communicable, and the stigmatisers' desire to protect themselves from contracting it. Symbolic stigma is defined as stigma that occurs because the condition (for example HIV infection) is linked to previously stigmatised and marginalised groups (Herek, 2002). Expression of symbolic stigma in a society will depend on the groups previously stigmatised; for example HIV-infected homosexual men and IDUs in the United States and CSWs in Sub-Saharan Africa face symbolic stigma (Herek, 2002). Deacon (2006) referred to this type of stigma as 'layered stigma', that is, the relationship between new forms of stigma and previously existing forms of exclusion and disadvantage among stigmatised groups. Accordingly, HIV-infected CSWs in Africa experience multiple layers of stigma because they are women, infected with HIV and CSWs (Nyblade, et al., 2003). Therefore, symbolic stigma is just another vehicle used to express hostility to previously marginalised groups and is used to justify further discrimination of members of that social group.

6.1.4 Outcomes of stigma

There is a range of outcomes of stigma, which include poorer health, decreased quality of life, denial of access to care, violence and poorer quality of work life (Holzemer, Uys, Makoae, et al., 2007). Some of the negative health behaviours that result from anticipated HIV-related stigma include delayed access to preventive and curative health, psychological and palliative care (Mahajan et al., 2008; Schuster et al., 2005). Unfortunately, these situations lead to a reduced ability to diagnose people with infectious diseases early, delayed control of the trajectory of the illness and reduced coping. Because PLHIV anticipate that they will be stigmatised, many will not access health facilities for follow-up treatment and other services, leading to the

worsening of symptoms in those with overt disease as well as continued transmission of HIV infection (Kipp, et al., 2007). Fear of stigma leads to avoidance of participation in PMTCT programs by pregnant women and their partners (Kipp, et al., 2007). Stigma also reduces adherence to PMTCT strategies, such as exclusive replacement breastfeeding (Eide et al., 2006).

Because of fear of stigmatisation, people with stigmatising conditions also try to avoid situations, or arrange their lives in order to avoid situations, where they could be forced to reveal their previously unknown stigma to others (Goffman, 1963). Thus, stigmatised people self-isolate, and they become anxious, hostile and suspicious. The stigmatised person is unsure of how they will be treated and reacts by 'defensive cowering', that is, they shy away from situations where their stigmatising condition may be exposed (Goffman, 1963). People with stigmatising conditions may also congregate into groups, a phenomenon called 'in-group alignments' (Goffman, 1963). In this situation, individuals who have the same stigma and suffer the same discrimination aggregate together. In grouping themselves together, stigmatised people develop a 'secessionist ideology' (Goffman, 1963). The HIV literature has increasingly documented that HIV-infected people are choosing each other based on their HIV status, also known as sero-sorting (Mao et al., 2006), thus physically or emotionally distancing themselves from those regarded as 'normal' (Kipp, et al., 2007).

However, Deacon (2006) argued that to only consider the negative outcomes of the stigmatisation process has limited the understanding of stigma and the range of effects it has on stigmatised people. She insisted that stigmatisation of PLHV does not necessarily lead to disadvantage or discrimination (Deacon, 2006). Some stigmatised individuals disavowed their imposed identity and challenged the dominant perspective that they are deviant (Alonzo & Reynolds, 1995). Thus stigmatised people will not always suffer low esteem and many continue to perform at high levels, are happy and resilient, and have a range of coping strategies (Dovidio, et al., 2000). Many PLHIV maintain positive attitudes, and constructively engage with their communities to reduce stigma and increase knowledge about HIV (Nyblade, et al., 2003). Positive activism by stigmatised people challenges stereotyping and discrimination and it can lead to improvement in the status and

overall physical and psychological health of the stigmatised population (Deacon, 2006).

6.1.5 Stigma management

Sandelowski (2004) defined stigma management as those actions people take in order to reduce the effects of stigmatisation including disclosure, passing, and normification. Disclosure was a major element of information control, but also a form of problem-focused coping (Medley, Kennedy, Lunyolo, & Sweat, 2009a). When a person conceals information about their potentially stigmatising attribute, they prevent others from knowing about it and thus avoid stigmatisation. Nevertheless, when a person fully discloses that attribute, they have to manage social situations where their stigma has become known (Goffman, 1963). This person moves from being 'discreditable' to being 'discredited', terms developed by Goffman (1963) to refer to different categories of stigmatised people whose stigma is unknown and those whose stigma is known, respectively.

The process of disclosure is fraught with complications, as the individual can be stigmatised as the new 'spoilt' identity emerges. Stigmatised people must be supported as they come to terms with their new identity, as it is probable that they will be stigmatised by family, friends and the community. However, some people do not disclose because they wish to avoid pity and to spare emotional pain to loved ones (Alonzo & Reynolds, 1995). Therefore major concerns for people with a potentially stigmatising condition would include to whom to disclose, and when and why to disclose. Among PLHIV, it is particularly important for them to choose carefully who to disclose to and with good reason, because un-strategic disclosure can lead to increased stigmatisation instead of support (Sandelowski, et al., 2004).

'Passing' refers to situations where people intentionally hide the fact that they have a stigmatising condition in an attempt to be considered 'normal' (Goffman, 1963). Many stigmatised people 'pass' in order to prevent overt incidents of stigmatisation and conserve their self-esteem (Alonzo & Reynolds, 1995). This is, however, fraught with complications because stigmatising conditions could become known to those considered 'normal' (Goffman, 1963; Herek, 2002). Passing is emotionally taxing (Alonzo & Reynolds, 1995), and unfortunately it prevents stigmatised people from

seeking necessary medical and psychosocial help, and increases levels of shame about having the condition (Alonzo & Reynolds, 1995; Herek, 2002). People with stigmatising conditions may also refuse to join peer groups where their condition may be identified and they are concerned about guilt by association (Alonzo & Reynolds, 1995).

Other negative consequences of passing include the eventual hostility from significant others when they find out that the individual has been hiding their condition (Alonzo & Reynolds, 1995). Another consequence is that individuals may continue to participate in certain activities so that people can remain unaware of their potentially stigmatising condition. For example, individuals infected with HIV may continue to have unprotected sex with unsuspecting partners (Alonzo & Reynolds, 1995). PLHIV may not suggest using condoms with their spouses for worry of being suspected to have HIV, as condom use in intimate relationships is suspect (Nyblade, et al., 2003). In other cases, mothers may continue to breastfeed their infants despite health workers' advice not to do so, in order to avoid judgement and interrogation from partners and family members (Eide, et al., 2006; Nyblade, et al., 2003). Some HIV-infected women in Africa do not tell their partners about their HIV status because of fear of violence, desertion or worry that they may be accused of bringing the infection into the relationship (Medley, et al., 2009a).

However, not all people with stigmatising conditions hide the fact. In normification, the stigmatised individual presents him/herself as an ordinary person without necessarily making a secret of his/her stigma (Goffman, 1963). Stigmatised people in these circumstances, work hard to dissociate themselves from negative stereotypes of being 'bad' or 'diseased' and present themselves as normal (Sandelowski, et al., 2004).

6.1.6 Interventions to reduce stigma

Interventions to combat stigma can be broadly classified into three groups: legal, policy interventions and programmatic interventions (Brimlow, Cook, & Seaton, 2003). Legal interventions provide legislation against discrimination of PLHIV while programmatic interventions include education programs, counselling,

development of coping skills for PLHIV, health workers and legislators among others, and provision of treatment for PLHIV, especially HAART.

Several programs have been developed to mitigate stigmatisation of PLHIV and are aimed at specific behaviours and attitudes that cause stigmatisation of PLHIV. These interventions are attractive because they are specific, they are easy to monitor and the outcomes are easy to measure and evaluate. Unfortunately, these programs are inadequate to combat the broader problem of stigma because they do not address the contextual factors, the fundamental causes of stigma and the reasons why it is so unrelenting (Link & Phelan, 2001). Link and Phelan (2001) believed that the approach to reducing stigma must be multi-faceted and multi-level: the former to combat the several forms of stigma and the latter to combat both individual and structural discrimination. Reduction in stigma can only happen when powerful groups that label, stereotype, separate, devalue and discriminate change their beliefs, attitudes, and behaviour; or at least when the power differences between the stigmatisers and stigmatised are reduced (Link & Phelan, 2001). Because individual and societal stigmatisation reinforce and are conditional upon each other, stigma interventions must be targeted at both levels (Herek & Glunt, 1988).

Weiss et al. (2006) proposed several multi-level interventions targeted at the individual with the stigmatising condition, others targeted at the people who stigmatise, some interventions targeted at eliminating or controlling the disease itself, and others interventions targeted at the community. Individual counselling could help PLHIV cope with their illness and teach them how to protect themselves from the impact of stigma. Individual and group interventions aim to enhance resilience in response to stigmatising encounters. Reeders (2009b) argued that the building of resilience among PLHIV should highlight stigmatisation as a social process and enhance development of internal and external resistance. Interventions aimed at the disease itself included HAART that would reduce the signs and symptoms of the disease and improve overall quality of life of PLHIV (Medley, et al., 2009a). Interventions for the general public would aim to correct misinformation about risks of transmission of the disease and also aim to enhance empathy with PLHIV (M. G. Weiss, et al., 2006). The fact that misconceptions around HIV still exist means that education of the community needs to improve the messages that are

relayed and provide accurate and in-depth information (Nyblade, et al., 2003). Health system interventions are equally important and health workers need to understand the role of the health system in mitigating or enhancing stigmatisation of PLHIV and how their conscious or unconscious stigmatising attitudes, thoughts and behaviour may negatively impact on PLHIV (Nyblade, et al., 2003).

Heijnders and Van Der Meij (2006) categorised stigma reduction strategies into intrapersonal, interpersonal, organisational/institutional, community, and government/structural interventions. They differentiated between strategies and interventions: the former defined as policies designed to achieve particular goals, while the latter were subsets of strategies and included actual activities carried out to reduce stigma. Intrapersonal stigma-reduction interventions include treatment, counselling and cognitive-behavioural therapy. These interventions are aimed at improving self-esteem and coping skills of PLHIV (Heijnders & Van Der Meij, 2006). Interpersonal level interventions target the PLHIV environment and they include care, education and support services for people who care for PLHIV, such as family members, and creation of home-based care teams.

Organisational or institutional interventions aim to change the stigma-enhancing aspects of health care systems and organisations or institutions that work with PLHIV (Heijnders & Van Der Meij, 2006), and include training programmes and policy development. Community targeted interventions include community education to improve general knowledge of HIV, allay misconceptions about transmission and change negative attitudes towards PLHIV. Governmental and structural level interventions should seek to enhance the protection of PLHIV's rights and monitor access to heath care and employment (Heijnders & Van Der Meij, 2006).

6.2 HIV-related stigma

From the mid-eighties, HIV-related stigma was identified as one of the major obstacles to the control of the HIV epidemic and Mann (1987) called it the 'third' epidemic, following that of the spread of HIV virus and increase of AIDS cases. Stigma contributes to the physical, psychological and social burden and may cause

equal, if not more, suffering than the disease itself (M. G. Weiss, et al., 2006). Stigma reduces positive health-seeking habits even in areas where the services are available (M. G. Weiss, et al., 2006) and increases stress levels among people who are stigmatised (Link & Phelan, 2006). Herek and Glunt (1988), defined AIDS-related stigma as "all stigma directed at persons perceived to be infected with HIV, regardless of whether they are actually infected and of whether they manifest symptoms of AIDS or AIDS-related complex (ARC)" (p 886). This definition included both individual and societal expressions of stigma towards PLHIV. Societal expressions of stigma included institutional and national policies that led to discrimination of PLHIV. HIV infection met Herek's (2002) definition of an enduring attribute that consigned those having it to a discredited and disadvantaged group.

Herek argued that HIV-related stigma was worse than stigma towards other diseases for three main reasons. Firstly, HIV was incurable and transmissible. Secondly, HIV infection was thought to be within the bearer's capacity to prevent and thirdly, because HIV was associated with marginalised and stigmatised groups (Herek, 2002; Herek & Glunt, 1988). AIDS was viewed as incurable and linked to an inevitable and unaesthetic death, contracted mainly by those who 'deserved to get it' (i.e. sexually promiscuous and homosexually active people and IDUs). It was associated with those who were thought to have character flaws and with disfiguring symptoms (Herek & Glunt, 1988).

As Deacon (2006) and Herek (2002) elaborated, the stigmatising syndrome was construed as preventable and within an individual's control to prevent - contracted through 'immoral' but 'voluntary and avoidable' behaviours that were associated with the stigmatised group - and therefore AIDS victims could be blamed and held responsible for their illness. AIDS was seen as a product of deviant behaviour: a metaphor for sinfulness and evil (Alonzo & Reynolds, 1995). Since AIDS was associated with those groups who were already stigmatised, it led to the further separation of 'us' from 'them', with the HIV-infected group constituting 'risk groups' as distinct from the 'general public' (Herek & Glunt, 1988). Institutional forms of stigmatisation enhanced and reinforced the beliefs, attitudes and behaviours of individuals towards PLHIV.

In studying the social psychology of HIV-related stigma, Herek and Glunt (1988) argued that HIV-related stigma is prevalent because of the anxiety that HIV infection elicits. Although HIV is no longer immediately fatal because of antiretroviral drugs, the fact that HIV can remain undetectable for a long time continues to elicit fear in the public. Despite the roll out of HAART, which controls HIV symptoms and prolongs life, HIV-related anxiety has not decreased and in some communities, the forms of stigmatisation have just changed (Roura et al., 2009). With the improvement in health of PLHIV, HIV now remains even more 'invisible' (Wilhelm-Solomon, 2010) and in some communities it has even been suggested that PLHIV should be labelled just so that people could tell that they were infected; or that they should be rendered impotent so that they do not continue to transmit the infection (Roura, et al., 2009). The general public worry that PLHIV might not do the 'right thing', that is, disclose their status to sexual partners or take measures to prevent onward transmission (Reeders, 2009a).

As discussed previously, HIV-related stigma also continued to exist because of the link of HIV to already marginalised groups. The prejudice that people had against HIV-infected people was just an extension of the prejudice they have against homosexual men, illegal drug users, prostitutes and ethnic minorities. Deacon (2006) stated that existing forms of stigmatisation against these groups were just layered onto HIV-related stigma; the fact that these groups were already marginalised and disadvantaged prevented them from resisting new forms of discrimination. Therefore HIV-related stigma was closely related to other forms of social discrimination, but became a separate and new form of social power with its own characteristics (Deacon, 2006).

Herek and Glunt (1988) argued that stigmatisation met the psychological needs of the stigmatisers. Because stigmatising groups deemed the 'risk groups' inferior to them, they were able to increase their own self-esteem and reduce their own anxiety (Dovidio, et al., 2000; Herek & Glunt, 1988). Dovidio et al. (2000) further argued that this self-esteem enhancement worked through the 'downward-comparison theory', where stigmatisers' self-esteem was enhanced when comparing themselves to others less fortunate than themselves, as well as through enhancing positive

dimensions of their group versus the stigmatised group. Stereotyping also served the social purpose of separating groups and perpetuating power and dominance over other groups; it legitimised stigmatisers' discriminatory acts and thus it could not be easily dispelled (Reeders, 2009b).

6.2.1 HIV-related stigma in Sub-Saharan Africa

In order to understand the process of stigmatisation in Northern Uganda, this section discusses stigmatisation of PLHIV in Sub-Saharan Africa and the unique social-cultural context that influences the expression of HIV-related stigma in this region. Sub-Saharan Africa continues to have high levels of HIV-related stigma, which remains one of the main obstacles to the provision of care for PLHIV in this region. PLHIV in this region, similar to other PLHIV elsewhere, face discrimination and are devalued, discredited, and considered 'tainted' and 'immoral'; yet there are some factors unique to the HIV-related stigma in Sub-Saharan Africa including cultural constructions, stereotypes and beliefs, HAART, and the role of religion and gender (Mbonu, Van den Borne, & De Vries, 2009).

Most cultures in Sub-Saharan Africa are predominantly collectivist (Triandis, 1989) where the individual is subordinate to the society and his/her thoughts, behaviour and feelings are secondary to those of the community. Societies that are highly collectivist are concerned about maintaining social structure, harmony, and preserving values (Mbonu, et al., 2009). These societies use several ways to control 'deviant' behaviour or behaviour that is negatively regarded (Alonzo & Reynolds, 1995). People who transgress are separated from the major group as they are considered to have created disruption in harmony. In relation to HIV-infection, PLHIV's past sexual histories are questioned and they are deemed as having lapsed from normal, properly sanctioned sexual behaviour.

In some communities, PLHIV are regarded as sexual deviants who have had socially unsanctioned sex. They are thought to be adulterers and prostitutes involved in shameful and immoral acts (Nyblade, et al., 2003). Therefore stigmatisation of PLHIV is a way of conserving social values, sanctioning 'deviant behaviours', asserting power and controlling sexuality in the society, and ultimately protecting the identity of the society (Mbonu, et al., 2009; Nyblade, et al., 2003). Concerns about

courtesy stigma are particularly important in Sub-Saharan Africa because people are interdependent on each other, and the presence of HIV may bring shame to the family or community (Mbonu, et al., 2009). Close relatives and friends sometimes discourage PLHIV from disclosing their HIV status and will sometimes go to extreme lengths to assist PLHIV to hide their HIV status, for example by helping them falsify HIV test results (Smith & Mbakwem, 2010).

The role of HAART in stigma in Sub-Saharan Africa is complex and the relationship between the two is discussed in more detail in the first paper appended to this chapter (Nattabi, et al., 2011a). Antiretroviral therapy and its delivery systems can either enhance or mitigate stigmatisation of PLHIV. Provision of HAART is rarely private in Sub-Saharan Africa because many antiretroviral programs rely on community and family members to support adherence among PLHIV, in place of health workers. In some cases, HAART and other support services to PLHIV are provided in open areas where community members can see who is coming in and out of the HIV clinic, and who is receiving treatment and other support (Wilhelm-Solomon, 2010). Therefore being on ARVs can inadvertently expose the previously hidden HIV-infected person's status and expose them to stigmatisation by family, friends and the community. Antiretroviral drugs assist in the reduction of symptoms and signs of HIV and thus in the reduction of overt as well as internal stigmatisation among PLHIV (Medley, et al., 2009a). With improvement in PLHIV's wellbeing and their ability to participate in social and economic activities, HAART also allows a reconstruction of their 'shattered and devalued' identities (Campbell et al., 2011).

Religion and gender also play a major role in mediating HIV-related stigma in Sub-Saharan Africa. Some religious groups and health facilities assist in the care and support given to PLHIV, thus reducing symptoms and signs as well as assisting with coping skills development among PLHIV (Campbell, Skovdal, & Gibbs, 2011; Nyblade, et al., 2003). Religious organisations can also lead to increased stigmatisation of PLHIV, increasing intolerance towards those considered 'deviant' (Alonzo & Reynolds, 1995; Campbell, Skovdal, & Gibbs, 2011; Otolok-Tanga, Atuyambe, Murphy, Ringheim, & Woldehanna, 2007). Some religious leaders link HIV infection with immorality, sin, and transgression, making it even harder for PLHIV to reveal their status or to access the services that they need. In some

countries, all prospective newlyweds are asked to test for HIV before their religious wedding ceremonies can be conducted (Smith & Mbakwem, 2010). In this way, the HIV status of individuals could be revealed to their communities, and sometimes churches may banish and stigmatise PLHIV.

In regards to the sexes, women in Africa are more likely than men to be stigmatised, devalued and face discrimination from their families, spouses and communities when diagnosed with HIV (Mbonu, et al., 2009). Women are considered the main vectors of the HIV epidemic, and they are either accused of transmitting the infection to their children or accused of being prostitutes and transmitting HIV to their clients and the general population. In fact, although many women acquire HIV during monogamous relationships, they are assumed to have acquired it because of promiscuity or through prostitution (Sandelowski, et al., 2004). In Sub-Saharan Africa, many women have to rely on their spouses and families for food, housing, access to land and other resources. Because of this vulnerable position and lack of power, female PLHIV in Sub-Saharan Africa suffer more than their male counterparts (Nyblade, et al., 2003).

Stigma also persists in Sub-Saharan Africa for other reasons. Though there is a high level of knowledge of basic aspects of HIV, there is a co-existing lack of in-depth knowledge of how is it spread, how long PLHIV can live, of how it is not spread and misconceptions (Nyblade, et al., 2003). Some people believe that HIV can be transmitted through casual contact or by breathing 'contaminated air'. Stigma is also deeply enmeshed with strong beliefs, moral judgements and fears around sex and death (Nyblade, et al., 2003).

Several studies have described the process of stigmatisation in Uganda. Some communities indicated that there was an overall reduction in stigma towards AIDS patients and their families in some parts of Uganda. Family caregivers of PLHIV in Western Uganda reported that stigmatisation of PLHIV had generally declined in their communities, with people more sympathetic and understanding towards PLHIV (Kipp, et al., 2007). Despite this, in rural southern Uganda several forms of stigma still exist: for example *received* stigma in the form of abuse and insults and *internal* stigma which prevents PLHIV from accessing health care and other support services (Muyinda, Seeley, Pickering, & Barton, 1997). In the 1980s, communities used

negative terminology to describe PLHIV, including words like *Kakokoolo* (scarecrow), *Yamira akaveera* (one who swallowed a piece of polythene bag), and *K'amuyoola* (one who was caught in a trap) (Muyinda, et al., 1997). Courtesy stigma is particularly strong in Uganda and many people have severed relationships with PLHIV in order to reduce the effects of stigma (Kipp, et al., 2007).

HIV-related stigma also has an impact on childbearing in Uganda. Kisakye et al. (2010) found that young women in Southern Uganda felt pressure to have children even when they were HIV-infected, because the society would question why they were married and not having children. Unfortunately, this had an impact on HIV transmission because they were unlikely to inform their partners about their HIV status, or attend PMTCT services. HIV-infected health workers in Uganda also experienced stigmatisation. A study of HIV-infected nurses in Luwero found that most of them had not disclosed their HIV status and would not receive antiretroviral care in the same facilities where they worked (Kyakuwa, 2009). These nurses encouraged lay people to disclose their HIV status; but they felt that the system would not be supportive enough if they, as health workers, disclosed their own HIV-infected status. They also felt that not enough attention was paid to health providers and there was a general lack of psychological support of HIV-infected health workers. In order to cope with the stress, but at the same time prevent any future stigmatising events, some of the nurses limited their social interactions with other health workers and employed selective disclosure, a mechanism they felt would protect them and provide a safe environment (Kyakuwa, 2009).

A study conducted in Northern Uganda by Wilhelm-Solomon (2010) found that unique to the stigmatisation of PLHIV in Northern Uganda was the prolonged civil conflict, with displacement of large numbers of civilians into IDP camps. People were forced to live in close proximity and because of this, PLHIV's HIV status was exposed to other people in the camps (Wilhelm-Solomon, 2010). In particular, because of the high visibility of HAART provision in the camps - which included open-air clinics, provision of food and unique utensils and commodities to PLHIV, and home-based care provided by known HIV counsellors and nurses - PLHIV's HIV status was inadvertently disclosed. Wilhelm-Solomon (2010) termed this,

'socio-spatial disclosure', a process by which their HIV status was revealed as they sought medical, psychological and other forms of care.

6.3 Stigma and its impact on the desire to have children among PLHIV

Stigma has a complex relationship with the desire and intent to have children among PLHIV. HIV-infected women who have experienced stigma, and those who fear rejection or have internal stigma, are more likely to continue to have children. At the same time, they tend to avoid informing their spouses of their serostatus (Aka-Dago-Akribi, et al., 1999; Cooper, et al., 2007; Craft, et al., 2007). In some HIV-infected women, having children improved feelings of self-worth (Craft, et al., 2007). In contrast, among PLHIV who have disclosed their HIV status or those who were concerned about further stigmatisation, stigma reduced the probability of having children (Craft, et al., 2007).

In an ethnographic study of people with HIV in Nigeria, Smith and Mbakwem (2010) documented that AIDS was still highly stigmatised and linked to promiscuity and breakdown of morals in Nigerian society. For some PLHIV in Nigeria, childbearing was a way of mitigating stigma, and of dissociating themselves from the negativity that comes with having HIV. Because of concerns about associated stigma, spouses become co-conspirators in hiding their partner's HIV status, sometimes going to great lengths such as forging HIV test results for the HIV-infected partners (Smith & Mbakwem, 2010). PLHIV in Nigeria were thought to have questionable sexual morals, hence having children and getting married were ways of disassociating themselves from being perceived as social and moral failures or being sexually promiscuous.

Therefore, based on this literature, this study sought to explore the experiences of stigma and the relationship between stigma and the desire to have children among PLHIV in post-conflict Northern Uganda. The next two papers present the findings and discuss the influence of stigma on the desire to have children among PLHIV in this region.

6.4 Article 2: Factors associated with perceived stigma among people living with HIV/AIDS in post-conflict Northern Uganda

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6.5 Article 3: Between a rock and a hard place: Stigma and the desire to have children among people living with HIV in Northern Uganda

Submitted: Journal of the International AIDS Society

6.6 Summary of the Chapter

This chapter provided a review of the concept of stigma, its types, outcomes, and management as well as stigma's relationship with the desire to have children among PLHIV. The next chapter will discuss access to contraception among PLHIV, and the factors associated with family planning use among PLHIV in Gulu, Northern Uganda.

CHAPTER 7: FAMILY PLANNING AMONG PLHIV

7.0 Introduction to the Chapter

This chapter discusses family planning use among HIV-infected men and women, factors associated with its use and family planning services available to PLHIV. The major component of the chapter is a peer reviewed article entitled: **Family planning among people living with HIV in post-conflict Northern Uganda: A Mixed Methods Study** (Nattabi, Li, Thompson, Orach, & Earnest, 2011b). This article combined the qualitative and quantitative analysis of family planning use among PLHIV in Gulu district, using the Social Ecological framework as a conceptual basis.

7.1 Family planning use among PLHIV

Several studies have found varying levels of use of family planning methods among PLHIV, with a range of methods being used. In Mbarara, Uganda, 85% of sexually active female PLHIV reported using a contraceptive method in the previous three months, with 84% of them using a barrier method, predominantly the male condom (Andia et al., 2009). In South Africa, 68% of HIV-infected women were using contraception (Peltzer, et al., 2008) and in Argentina, 80% of sexually active women and 75% of men who were not seeking to have any more children used contraception (Gogna, Pecheny, Ibarlucía, Manzelli, & López, 2009). A longitudinal study in Malawi found a high level of use of contraception in a female cohort of PLHIV, ranging from 59.5% to 67.5% over a one-year period (Taulo, et al., 2009), though only about 4% were using condoms. A study in Western Uganda compared the use of contraception between HIV-infected and HIV-negative participants and found that a significantly higher proportion of HIV-infected people (74%) were using contraception compared to 13% of HIV-negative participants ($p < .0001$) (Heys, et al., 2009). This study found a very high level of unmet need for effective contraception among these HIV-infected participants with over 90% of them unable to access this type of contraception. The HIV-infected participants mainly used a condom, mostly to avoid re-infection.

Another Ugandan study found a high level of use of contraception with male condoms being the major form of contraception used (Homsy, et al., 2009). Over 60% of sexually active female PLHIV were using condoms, but only an estimated 13% were using a semi-permanent (pills, injections or implants) or permanent (tubal ligation) methods, and fewer than 5% were using dual contraception. What was significant in this study was that of the 176 sexually active women who said they did not want to have children, 33% were not using any contraception, 53% were using condoms only, 86.4% were not using a reliable method and 96% were not using dual contraception (Homsy, et al., 2009). Dual contraception is essential to prevent infection or re-infection of sexual partners and prevent future pregnancies. In the United States, more than 30% of female PLHIV reported not using any contraception, although 40% of these women had at least one heterosexual encounter in the previous six months. The majority of pregnancies occurred among HIV-infected women who ostensibly did not intend to conceive (Massad et al., 2007). In Jinja, Uganda, 33% of a sexually active group of PLHIV engaged in "pregnancy risk behaviours", having inconsistent or no condom use without any other form of family planning method with at least one sexual partner in the three previous months (Nakayiwa, et al., 2006).

Several studies conducted in Uganda have reported high levels of contraception use among PLHIV, ranging from 58% to 85% of participants (See Table 1 for summary of studies) (Andia, et al., 2009; Heys, et al., 2009; Homsy, et al., 2009; Maier, et al., 2009; Nakayiwa, et al., 2006; Wanyenze, et al., 2011). Particularly, Wanyenze et al. (2011) compared contraception use across several HIV clinics in Uganda, including TASO and Gulu National Referral Hospital HIV clinics in Gulu, Northern Uganda, and found that women in Gulu were the least likely to be using modern methods of contraception in comparison to PLHIV from clinics in other parts of Uganda. Though overall contraceptive prevalence rates among HIV-infected women in Kampala and Kabarole HIV clinics were 84% and 85%, respectively, only 58% of HIV-infected women in Gulu were using any family planning method (Wanyenze, et al., 2011). Another population-based study of civil-conflict areas, including Northern Uganda, West and South Darfur, Southern Sudan and Eastern Congo confirmed the low contraceptive prevalence in Gulu district at 16.2%, despite high levels of knowledge about family planning in this region at 92.6% (McGinn et al., 2011).

Family planning methods used in different HIV-infected populations vary. In the United States, 30.5-36.3% of HIV-infected women used barrier methods, less than 10% used hormonal contraception, while a significant number used sterilisation (21.8%-26.5%). Vasectomy, however, catered for less than 1% of sterilisation methods (Massad, et al., 2007). Female sterilisation was high among PLHIV in the Dominican Republic, India and Thailand, all countries with high levels of female sterilisation in the general population (Rutenberg & Baek, 2005). In South Africa, the most common methods of contraception among a group of HIV-infected women were male condoms (50%), hormonal injections (35.3%) and the pill (12.9%) (Peltzer, et al., 2008). Intrauterine devices, rhythm methods, male sterilisation, withdrawal and spermicides were less commonly used (Andia, et al., 2009; Massad, et al., 2007).

In Argentina, physicians' emphasis on condoms to prevent pregnancies and re-infection resulted in a high percentage of patients using condoms (Gogna, et al., 2009). Although dual use of contraceptives in some populations has generally remained low (Gogna, et al., 2009), use of barrier methods with sterilisation or hormonal contraception among HIV-positive women in the United States, has significantly increased over time (Massad, et al., 2007). In Mbarara, Uganda, dual methods were practised among HIV-infected female PLHIV, with more than half of those using hormonal methods; 60% of sterilised women and 60% of those who were using other methods used a barrier method as well (Andia, et al., 2009).

7.2 Factors influencing the use of family planning among PLHIV

In the literature, there are several factors associated with the use of family planning methods among PLHIV. Non-use of contraception among PLHIV in Jinja, Uganda was found to be significantly associated with a lack of formal education, lack of knowledge of PMTCT, and a desire for children among male and female participants (Nakayiwa, et al., 2006). In the Mbarara district of Uganda, the use of contraception among female PLHIV, specifically barrier methods, was significantly associated with the use of HAART and no desire to have children (Andia, et al., 2009). In another Ugandan study in Rakai, increased use of hormonal contraceptives was associated

with higher educational level, higher socioeconomic status, higher number of previous births, higher number of sexual partners, being in a stable relationship, and open discussion of family planning methods with their spouse. In contrast, fewer sexual partners, use of condoms, breastfeeding and the presence of opportunistic infections were associated with a lower use of hormonal contraceptives (C. Polis et al., 2009). A study across several HIV clinics in Uganda found that the use of contraception among non-pregnant women, who were married or in de facto relationships, was associated with the disclosure of HIV status and discussion of number of children with their partner (Wanyenze, et al., 2011).

Qualitative studies have also documented other factors that impact on the use of contraception among PLHIV. Some include fear of side-effects, convenience and protection against STIs, and/or possible re-infection with HIV (Laher et al., 2009). In Soweto, South Africa, a number of women preferred to use condoms because they were associated with fewer side-effects and protected against STIs, but their use required the participation and agreement of the male partners, some of whom were reluctant to use them because of reduction in pleasure and connotations of infidelity (Laher, et al., 2009). Some of the women preferred injectable contraceptives because they were convenient and it was possible to hide their use. The desire of their male partners to have children also impacted on whether women were able to use contraception.

The impact of male attitudes on their spouses' use of contraception has long been documented. Ezeh (1993) detailed the strong influence that men wielded over their wives, whereby men felt that their wives had no right to determine how many children they could have, no right to ask them to use condoms, and no right to use contraception without their husband's explicit permission. Women were expected to obey the 'rules' of the men and any woman who didn't, risked being beaten. Ezeh documented that a woman's contraceptive use depended on her husband's characteristics, but she was not able to influence her husband's attitude to family planning.

7.3 Family planning counselling and services for PLHIV

Many authors acknowledge the need to provide integrated HIV and family planning services (Baek & Rutenberg, 2005; Berer, 2004; Cooper, et al., 2007; Segurado & Paiva, 2007). Some studies have found that there is a broad demand for contraceptives among PLHIV and many HIV-infected women would like to use them if available (Adair, 2007; Baek & Rutenberg, 2005). Some studies have documented high levels of unwanted pregnancies among female PLHIV, with up to 55% of pregnancies among a group of HIV-infected women in Tanzania being unwanted. In Cote d'Ivoire, 57% of sexually active postpartum women did not use contraception but did not want to get pregnant (Duerr, Hurst, Kourtis, Rutenberg, & Jamieson, 2005). However, access of PLHIV to family planning services varies. For example in South Africa, 76.3% of HIV-infected women received counselling on safe sex during pregnancy, while 92.2% said that the health care provider discussed family planning at postnatal care (Peltzer, et al., 2008). But there were also missed opportunities to discuss family planning with both HIV-positive and negative clients occur at some health facilities. In a study in Nairobi, Kenya, 50% of HIV-positive and 58% of HIV-negative PMTCT attendees interviewed reported that health providers had not discussed family planning with them on that day, or on any previous visits to the clinic (Baek & Rutenberg, 2005).

Delivery of family planning services to PLHIV was sometimes hampered by structural level problems and difficulties. In many developing countries, these included lack of policies or lack of translation of policy into practice, lack of funds, lack of research or evidence on which to base allocation of resources and bureaucratic delays (Obare, Birungi, & Kavuma, 2011). For instance, information from various stakeholders including policy makers, funders and implementers of sexual and reproductive health programs in Uganda indicated that there were adequate policies to govern the implementation of activities in this area. However, the implementation of these policies was hampered by lack of infrastructure, low staffing, lack of skills, lack of guidelines and training materials, the large number of clients and lack of time (Obare, et al., 2011).

It is worth noting that sometimes, despite provision of family planning services and counselling of PLHIV, not all will take up the services and the reasons for this need further investigation. At an HIV clinic in Eastern Uganda, a range of services were

made available to the attendees with regular counselling, referral and follow-up. Despite this, over 86% of sexually active women who said they didn't want more children, were only using condoms and no other method of reliable contraception (Homsy, et al., 2009). In the same group of women, over a third said they didn't want to have children, but were not using any contraception at all despite referral to a family planning clinic. Other studies have also shown that despite exposure to health education and provision of services, change in contraceptive behaviour among PLHIV over time was minimal (Massad, et al., 2007) or at least not optimal (Belzer et al., 2001) with low use of contraception among HIV-infected women despite regular and consistent advice against conception (Nebié, et al., 2001). In order to ascertain the reasons for low use of contraception among PLHIV who reported not wanting any more children, an in-depth evaluation is required. Possibly side-effects, health concerns and spousal desires to have children are possible explanations for this incongruity.

7.4 Family Planning and PMTCT

Several authors argue that efforts to prevent MTCT of HIV can focus on reducing the fertility level of HIV-positive women, especially in high prevalence countries (Adair, 2007; Reynolds, Steiner, & Cates, 2005; Sweat, O'Reilly, Schmid, Denison, & de Zoysa, 2004). Furthermore, family planning programs are as effective as PMTCT programs in reducing MTCT of HIV (Reynolds, et al., 2005; Sweat, et al., 2004). An analysis of PMTCT programs in eight African countries found that a 16% reduction in unintended pregnancies among HIV-infected women would yield an equivalent reduction in HIV infant cases as the current nevirapine-based PMTCT interventions in those countries (Sweat, et al., 2004). Reynolds (2005) also found that an increase in contraceptive use leads to a greater reduction in HIV-positive births at the same level of expenditure as provision of nevirapine. Halperin et al. (2009) estimated that globally it would cost 690 USD to avert each infant HIV infection by using the PMTCT programs. If all unmet need was met for all HIV-infected women, an additional 371 USD would be the cost of averting an infant infection by preventing unintended pregnancies and it would cost only 63 USD per birth averted. In other words, though the PMTCT programs can avert infant HIV infection, preventing unwanted pregnancies among women infected with HIV would not only reduce

infant infections, it would prevent unwanted births and have other flow on effects such as improving the health of the mother, reducing the number of orphans in the future, reducing the amount of money spent on paediatric ART, and also reducing maternal morbidity and mortality.

Considering the high unmet need among PLHIV (Myer, Rebe, & Morroni, 2007) and a broad demand for contraceptives among women living with HIV (Adair, 2007; Baek & Rutenberg, 2005), integration of HIV services with family planning services could improve reproductive health outcomes (Baek & Rutenberg, 2005; Berer, 2004; Cooper, et al., 2007; Segurado & Paiva, 2007), as well as contribute to reducing paediatric HIV infections (WHO/UNFPA/UNAIDS/IPPF, 2005). This is particularly important in countries such as Uganda where MTCT is one of the major routes of HIV transmission with 18% of all new HIV infections being attributable to MTCT alone (Wabwire-Mangen, et al., 2009). Unfortunately, efforts to reduce MTCT of HIV are hampered by the fact that only a small proportion of HIV-infected women know that they are infected (Adair, 2007). In Uganda, for example, awareness of MTCT is low and the uptake of PMTCT services is limited, particularly due to numerous programmatic, social, cultural and economic factors (Ministry of Health - The Republic of Uganda, 2003).

The next peer-reviewed article reports on the knowledge of, access to and factors associated with family planning use among the study respondents. The article explores the barriers that need to be overcome in order to improve access to family planning services to those PLHIV who need them, together with the possible multi-level interventions that can be implemented by a variety of organisations.

7.5 Article 4: Family planning among people living with HIV in post-conflict Northern Uganda: A Mixed Methods Study

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Family planning among people living with HIV in post-conflict Northern Uganda: A mixed methods study

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Abstract

Background: Northern Uganda experienced severe civil conflict for over 20 years and is also a region of high HIV prevalence. This study examined knowledge of, access to, and factors associated with use of family planning services among people living with HIV (PLHIV) in this region.

Methods: Between February and May 2009, a total of 476 HIV clinic attendees from three health facilities in Gulu, Northern Uganda, were interviewed using a structured questionnaire. Semi-structured interviews were conducted with another 26 participants. Factors associated with use of family planning methods were examined using logistic regression methods, while qualitative data was analyzed within a social-ecological framework using thematic analysis.

Results: There was a high level of knowledge about family planning methods among the PLHIV surveyed (96%). However, there were a significantly higher proportion of males (52%) than females (25%) who reported using contraception. Factors significantly associated with the use of contraception were having ever gone to school [adjusted odds ratio (AOR) = 4.32, 95% confidence interval (CI): 1.33-14.07; p = .015], discussion of family planning with a health worker (AOR = 2.08, 95% CI: 1.01-4.27; p = .046), or with one's spouse (AOR = 5.13, 95% CI: 2.35-11.16; p = .000), not attending the Catholic-run clinic (AOR = 3.67, 95% CI: 1.79-7.54; p = .000), and spouses' non-desire for children (AOR = 2.19, 95% CI: 1.10-4.36; p = .025). Qualitative data revealed six major factors influencing contraception use among PLHIV in Gulu including personal and structural barriers to contraceptive use, perceptions of family planning, decision making, covert use of family planning methods and targeting of women for family planning services.

Conclusions: Multilevel, context-specific health interventions including an integration of family planning services into HIV clinics could help overcome some of the individual and structural barriers to accessing family planning services among PLHIV in Gulu. The integration also has the potential to reduce HIV incidence in this post-conflict region.

Keywords: HIV/AIDS, contraception, mixed methods, Northern Uganda

Background

Between 1987 and 2007, Northern Uganda was affected by civil conflict resulting in a complex humanitarian emergency, characterized by a displacement of over 1.5 million people from their homes into overcrowded internally displaced persons (IDP) camps. The region experienced an increase in transmission of infectious diseases and increased mortality rates [1]. In 2006 Northern Uganda had the highest infant mortality rates (106 deaths per 1,000 live births) and under-five mortality (177 deaths per 1,000 live births) in all of Uganda, with even higher rates in the IDP camps at 123 and 200, respectively [2]. During the insurgency, disruptions to the health care system and social infrastructure, and migration of skilled health workers to more stable parts of the country led to limited availability of, and access to, quality health services among the IDPs [1].

Consequent to the insurgency, Gulu District had the highest percentage of its population (58.1%) in the lowest quintile of wealth in Uganda, and only 0.9% of females and 3.0% of males had completed secondary education [2]. Northern Uganda also had the lowest use

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of contraceptives by currently married women aged 15-49 years: only 10.9% of women were using family planning methods in 2006 [2]. The total unmet need for family planning in the Northern region was 46% among currently married women (compared with 41% nationally), with 29.5% of these women unable to access family planning services to help space births and 16.5% unable to limit their family size. Overall, only 19.1% of total demand for family planning was being met in Northern Uganda, the lowest percent in the whole country and the total fertility rate was 7.5 children, one of the highest rates in the country [2].

Despite being a largely rural area, in 2004, the prevalence of HIV for the North Central Uganda region reached 8.2% (9.0% for women and 7.1% for men), one of the highest in Uganda, and in contrast to a national average of 6.4% and other predominantly rural areas such as the West Nile region (2.3%) [3]. The displacement of populations, food insecurity leading to transactional and survival sex, where sex was exchanged for basic survival with an element of exploitation by older, and wealthier men, and rape by combatants were considered to be the key drivers of the high prevalence of HIV in post-conflict Northern Uganda [4].

However, despite the poor health and social indicators in Northern Uganda [1,2], there is limited information about PLHIV in the region, especially around individual, social, cultural and structural impediments to health care due to the protracted conflict, which limits evidence-based allocation of resources. Other quantitative studies have documented factors associated with contraception use among PLHIV in Uganda [5-7] but the circumstances in Northern Uganda warrant a detailed exploration. Underpinned conceptually by the Social Ecological Framework which proposes that an individual's behavior is influenced by several factors at a multitude of levels [8,9], this mixed-methods study aimed to determine the knowledge of, access to and, factors associated with use of family planning methods among PLHIV in Gulu District, Northern Uganda.

Methods

Setting

Gulu District is situated in the Acholi-sub region of Northern Uganda and has a population of 581,740 people [10]. According to the 2002 Uganda census, a quarter (25%) of the population was living in Gulu town, with the rest either in IDP camps or in the rural areas [11]. Gulu town, the economic capital of the northern region, is 332 kilometers north of the capital city, Kampala.

Recruitment of respondents

A mixed-methods design constituting a survey and semi-structured interviews was selected for this study. Between February and May 2009, 476 PLHIV were recruited to take part in the study. These respondents attended three HIV clinics within Gulu municipality area: St. Mary's Hospital, Lacor, Gulu National Referral Hospital (GNRH) and The AIDS Support Organization (TASO) clinic. The sample size was calculated on the premise that 50% of the sample would desire to have children (the key outcome of the overall larger study), with an acceptable sampling error of 5% and at 95% level of confidence. The selection criteria for respondents in this study were HIV-infected women and men aged 15-49 years, attending outpatient HIV clinics in Gulu District, and consenting to participate in the study, regardless of length of time attending the clinic or highly active antiretroviral therapy (HAART) history. Pre-determined quotas by clinic, age and sex were used to ensure that a sufficient number of respondents for both sexes and relevant age groups were recruited. Thus equal proportions (14.3%) of respondents were recruited in each age group i.e. 15-19, 20-24, 25-29, 30-34, 35-39, 40-44, and 45-49 year groups. Seven trained interviewers approached consecutive clients attending these three clinics and asked them to participate in the study and recruitment continued until these quotas were filled.

Data collection procedures

A 121-item questionnaire was administered to each respondent to collect socio-demographic information, sexual and reproductive history, family planning knowledge and use, fertility desires and intentions and experiences of stigma. The questions on women's and men's fertility desires and contraceptive use were adopted from the 2006 Uganda Demographic and Health Survey (UDHS) [2]. For the purpose of this study, contraception use was defined as the use of any modern or traditional method to prevent a pregnancy [2]. Modern methods included female and male sterilization, the oral contraceptive pill, intrauterine device, injectables, implants, male and female condoms, lactational amenorrhoea and emergency contraception. Traditional methods included periodic abstinence and withdrawal.

To collect information about family planning knowledge, the respondents were asked to name ways or methods by which a couple could delay or avoid pregnancy. If a respondent failed to mention a particular method spontaneously, the interviewer described the method and asked whether the respondent had heard of it, and if they had ever used the method. This form of prompting was used in case the respondent knew the method by another name or knew the method but not its name. The respondents were asked if they were currently using any method to prevent a future pregnancy. For this study, use of contraception by the spouse was also considered use by the respondent: for example, if the husband of the female respondent was using

condoms, she was considered to be using condoms as a contraception method.

The respondents were asked where they obtained contraception and sources of information on family planning methods, methods they preferred, reasons for not using contraception, and whether health workers at the facility had ever discussed family planning with them. The respondents in long term stable relationships (married or de facto) and those who were separated, divorced or widowed were also asked if they had discussed family planning methods with their spouses in the past. They were also asked about the status (alive or dead) and sex of their biological children. The female respondents were asked if they were currently pregnant. All respondents were asked whether they desired to have children in the future.

The respondents were also asked about HIV transmission routes and antiretroviral therapy. They were also asked about the length of time since HIV diagnosis, the length of time attending the HIV clinic, if they were on highly active antiretroviral therapy (HAART) and, if so, the length of time on HAART. The respondents in long term relationships and those who were separated, divorced or widowed were also asked about their spouses' HIV status and if they had disclosed their own HIV status to their spouse. Complete knowledge about prevention of mother-to-child transmission (PMTCT) was defined as being able to correctly name the three routes of HIV transmission from mother to child i.e. during pregnancy, delivery and while breastfeeding.

For the qualitative arm of the study, three interviewers explored the experiences of family planning and service provision with 26 participants, using a semi-structured guide. The selection criteria for these participants were being HIV-infected, aged 15-49 years, living in Gulu District and consenting to participate in the study. These semi-structured interviews were held in the privacy of the participants' homes, out of hearing range of other family members and neighbours to ensure confidentiality. The interviews lasted between 1-2 hours. All the interviews were conducted in Luo, audiorecorded, then transcribed and translated into English.

The first author also interviewed United Nations Population Fund (UNFPA) staff members, managers of Marie Stopes International, Uganda and Reproductive Health Uganda and Family Health International, and officials from the Ministry of Health, Uganda in order to determine the availability and coverage of HIV and family planning services in Gulu. These officials were also asked about the amount and sources of funding for family planning services for the general population, whether there were specific family planning programs for PLHIV and the level and type of family planning training that health workers had received.

The study received ethical approval from the Curtin University Human Research Ethics Committee, the Makerere University School of Public Health Institutional Review Board, and the Uganda National Council for Science and Technology (UNCST). In order to ensure that respondents were able to give informed consent, the interviewers read out a prepared translated information sheet where the respondents were informed about the objectives, procedures and implications of the study. Respondents were informed that they were free to withdraw at any stage in the study and provided either written or thumb-printed consent.

Analyses

Quantitative data were analyzed using SPSS Statistics Version 19 for Windows (SPSS Inc, Chicago, Illinois, USA). Socio-demographic characteristics and the reproductive and HIV history of the respondents were summarized using proportions for categorical variables and medians with interquartile ranges for continuous variables. Separate analyses were conducted for males and females to determine the magnitude of differences in knowledge of contraception, current family planning use and preferred family planning methods. Bivariate analysis was conducted to determine the association between current use of family planning and the independent variables. Factors significantly associated at the $p < .10$ level in bivariate analysis with current use of family planning were evaluated in multivariate logistic analysis. A sub-analysis was conducted to determine the factors independently associated with current use of barrier and hormonal methods of contraception, because they serve different purposes and require different actors for their use. The former methods of contraception also function to prevent HIV/STI transmission and mainly require male participation and cooperation while the latter are used by females. The strengths of associations are presented as odds ratios (OR) or adjusted odds ratios (AOR) with 95% confidence intervals (CI).

Qualitative data were managed using Nvivo8 software (QSR International Pty Ltd). Interview transcripts were systematically read and reread to ensure familiarity with the content, and initially coded using an open coding method [12]. A coding framework was developed to identify dominant themes and subthemes related to family planning experiences. Some of the themes were adopted from the literature, while others emerged from the data. The cases and quotes that illustrate the themes best [13] are presented in this paper.

Results

Quantitative results

Sample characteristics

Four hundred and seventy six respondents (238 males and 238 females), were recruited into this arm of the

study. Ninety eight respondents (20.6%) were from Gulu National Referral Hospital (GNRH), 168 (35.3%) from St. Mary's Hospital, Lacor, and 210 (44.1%) from The AIDS Support Organization (TASO) clinic (Table 1). Eighty two percent of respondents had ever attended school, but 45.9% (179/390) had less than 7 years of primary education, and only 6.4% (25/390) had attended university or other tertiary institutions. Seventy two percent were of the Roman Catholic religion. Fifty percent of respondents were in a long term stable relationship (married or de facto), with 28.4% of these respondents in polygamous relationships; 46.9% were peasant farmers, and 48.3% were living in urban areas (towns/trading centres).

Table 1 Sociodemographic characteristics, reproductive and HIV history of PLHIV in Gulu District, Uganda, February-May 2009 (n = 476)

Characteristic	Number	Percent
Sex		
Male	238	50.0
Female	238	50.0
Clinic attended		
GNRH	98	20.6
Lacor	168	35.3
TASO	210	44.1
Education		
Never attended school	85	17.9
Some primary education	179	37.6
Completed primary education	84	17.6
Some secondary education	87	18.2
Completed secondary	16	3.3
Tertiary education	25	5.3
Missing	1	0.2
Religion		
Roman Catholic	340	71.5
Other	131	27.5
Missing	5	1.0
Relationship status		
Never married	76	15.9
Married/De facto	236	49.6
Separated/Divorced/Widowed	164	34.5
Polygamy (if married/de facto)		
Monogamous	169	71.6
Polygamous	67	28.4
Occupation		
Peasant farmers	222	46.9
Professionals	24	5.1
Others	230	48.0
Residence		
Town/Trading centre	230	48.3
Village	204	42.9
IDP camp	41	8.6
Other	1	0.2
Reproductive history		
Respondents who have ever had children	397	83.4
Respondents who had ever lost a child	137	34.9
Currently pregnant (females only)	18	7.6
Respondents on HAART [a]	236	49.8
Time on HAART (months) [b]		
Less than 24 months	112	47.7
24 months and more	123	52.3
Spouse's HIV status [c]		
Positive	213	53.3
Negative	49	12.1
Not applicable/unknown/missing	138	34.6
Disclosure of HIV status to spouse [c]		
Yes	268	66.9
No	61	15.3
Unknown/missing	71	17.8
Complete PMTCT knowledge	319	67.0

GNRH, Gulu National Referral Hospital; HAART, Highly Active Antiretroviral Therapy; IDP, Internally displaced people; TASO, The AIDS Support Organization; [a] data for 2 respondents missing; [b] data for one person on HAART missing; [c] single respondents excluded

Eighty-three percent of the respondents had ever had children and 34.9% (137/392) had also lost a child. Eighteen female respondents (7.6%) were pregnant at the time of the study. The median number of children born to the respondents was 3 (interquartile range 1-5). Fifty percent of the respondents were on HAART, with 52.3% of them having been on HAART for 24 months or longer. Of the respondents in long term stable relationships or those who had been separated, divorced and widowed, 53.5% had an HIV positive spouse. Eighty one per cent (268/329) had disclosed their HIV status to their spouse. Sixty-seven per cent of the respondents knew all the three routes of HIV transmission from mother to child i.e. during pregnancy, delivery and while breastfeeding.

Knowledge and use of family planning

The majority of respondents (96%) knew at least one method of family planning (Table 2). Fifty nine percent had discussed family planning with a health worker while 62.6% of those in long term relationships or separated/divorced/widowed had ever discussed family planning with their spouse. Though 70% of all respondents had used a family planning method in the past, only 38% were currently using any method. Twenty seven percent were currently using a barrier method of contraception. While there was no difference in knowledge of, and past use of family planning methods by sex, there were statistically significant differences in the proportion of male

Table 2 Family planning knowledge, discussion and use among PLHIV in Gulu District, Uganda, February-May 2009 (n = 476)

Variable	All n = 476	Males n = 238	Females n = 238	p value *
	n (%)	n (%)	n (%)	
Have knowledge of at least one family planning method	457 (96)	230 (97)	227 (96)	0.482
Have ever discussed family planning with health workers[a]	281 (59)	129 (56)	152 (66)	**0.037**
Have ever discussed family planning with their spouse[b, c]	224 (63)	122 (72)	102 (54)	**0.000**
Have past history of using any family planning method	330 (70)	165 (69)	165 (70)	1.000
Currently using any form of family planning[d]	181 (38)	121 (52)	60 (25)	**0.000**
Currently using a barrier method of family planning	126 (27)	100 (42)	26 (11)	**0.000**

* p value calculated using Pearson's chi square; [a] missing data for 15 respondents; [b] single respondents excluded; [c] missing data for 42 respondents; [d] missing data for 8 respondents.

and female respondents who had discussed family planning with health workers and spouses, and those currently using family planning methods. Significantly more women (66%) had discussed family planning with health workers than men (56%), but conversely, significantly fewer women (54%) had ever discussed family planning with their spouse in comparison to the male respondents (72%). About half of the male respondents (52%) reported that they were currently using a method of family planning, compared to only 25% of the female respondents.

The male condom was the most commonly known method (99.4%), followed by the pill (88.3%) and injectables (87.5%). Male condoms were also the most commonly used form of contraception (69.2%), followed by the injectables (19.4%), then periodic abstinence (10.9%). Among the respondents who were currently using contraception methods, eighty-two percent of males compared to 41.3% of females were using the male condom. However, only 17% were using dual methods, that is, a male condom and another method at the same time. In Uganda, the condom is generally promoted as a means to prevent HIV transmission rather than as a family planning method [5]. When the male condom was excluded from the analysis, only 18% (88/476) of the respondents were using a method generally considered as a means of preventing pregnancy. The majority of the clients preferred to use condoms (30.3%), followed by injectables (28.7%) and the pill (17.1%). Most of the respondents had heard about family planning on the radio (89.4%) and other sources of information included newspapers (25.5%), posters (25.4%), TV (8.7%) and video (11.7%).

Forty-three percent (184/430) of the respondents desired to have more children, significantly more males than females (54.2% vs. 31.7% respectively; Pearson's chi square = 35.248, d.f. = 1, p = .000). Of the 246 respondents who said they did not desire to have any more children, 59.3% (146) were not using any method to prevent further pregnancies: 34% of the 97 men and 76% of the 148 women who reported they did not want any more children, were not using any form of contraception. There was no difference in whether respondents had discussed family planning with health workers by clinic attended (Pearson's chi square = .030, d.f. = 1, p = .863).

Bivariate analysis (Table 3) showed that current family planning use was significantly associated (at the $p < .05$ level) with being male, being married or in a de facto relationship, having ever gone to school, having at least one child, not having had a death of a child, having discussed family planning with a health worker and spouse, attending TASO or Gulu National Referral clinics, having adequate knowledge about PMTCT, and spouse's lack of desire for children. In multivariate analysis (Table 3), having ever gone to school [adjusted odds ratio (AOR) = 4.32, 95% confidence interval (CI): 1.33-14.07; p = .015], discussion of family planning with a health worker (AOR = 2.08, 95% CI: 1.01-4.27; p = .046), or with one's spouse (AOR = 5.13, 95% CI: 2.35-11.16; p = .000), not attending the Catholic-based clinic (AOR = 3.67, 95% CI: 1.79-7.54; p = .000) and spouse's non-desire for children (AOR = 2.19, 95% CI: 1.10-4.36; p = .025) remained significantly associated with the current use of contraception.

On further multivariate analysis of the association between the independent variables and the current use of barrier methods and hormonal methods, the following remained significant: male sex (AOR = 7.29, 95% CI: 3.73-14.29), being in a stable relationship (AOR = 4.46, 95% CI: 2.04-9.80), discussion of family planning with one's spouse (AOR = 9.06, CI: 3.98-20.61), and not attending the Catholic-based clinic (AOR = 4.75, 95% CI: 2.44-9.28) were significantly associated with use of barrier methods. Being in a stable relationship (AOR = 2.30, 95% CI: 1.09-4.85), and discussion of family planning with a health worker (AOR = 5.62, 95% CI: 2.03-15.62) were significantly associated with use of hormonal contraception.

Qualitative results

Six key themes around factors influencing contraception use among PLHIV were identified from the analysis of semi-structured interviews with clients and staff in the

Table 3 Factors associated with current family planning use among PLHIV in Gulu District, Uganda, February-May 2009

Variable	Total n	Currently using a family planning method n (%)	OR (95% CI)	p value	AOR (95% CI)	p value
Age group [a]						
15-29 years	199	68 (34.2%)	1.00			
30-49 years	269	113 (42.0%)	1.39 (0.95-2.04)	0.085		
Sex [a]						
Female	236	60 (25.4%)	1.00		1.00	
Male	232	121 (52.2%)	3.19 (2.17-4.72)	**0.000**	1.90 (0.91-3.97)	**0.085**
Marital status [a]						
Single/divorced/widowed	232	48 (20.7%)	1.00		1.00	
Married/de facto	236	133 (56.4%)	4.90 (3.26-7.37)	**0.000**	2.19 (0.98-4.88)	**0.055**
Type of marriage (if married or de facto) [b]						
Polygamous	66	37 (56.1%)	1.00			
Monogamous	169	95 (56.2%)	1.01 (0.57-1.79)	0.983		
Residence [c]						
Rural	241	90 (37.3%)	1.00			
Urban	226	91 (40.3%)	1.13 (0.78-1.64)	0.517		
Education [c]						
No	85	17 (20.0%)	1.00		1.00	
Yes	382	164 (42.9%)	3.03 (1.69-5.26)	**0.000**	4.32 (1.33-14.07)	**0.015**
Number of children [c]						
0 children	73	20 (27.4%)	1.00			
1 child and more	394	161 (40.9%)	1.83 (1.05-3.18)	**0.030**		
History of death of child [d]						
Yes	135	42 (31.1%)	1.00			
No	225	117 (45.9%)	1.88 (1.21-2.91)	**0.005**		
Discussion of family planning with health workers [e]						
No	179	43 (24.0%)	1.00		1.00	
Yes	278	137 (49.3%)	3.07 (2.03-4.66)	**0.000**	2.08 (1.01-4.27)	**0.046**
Discussion of family planning with spouse [f, g]						
Never	134	20 (14.9%)	1.00		1.00	
At least once	224	131 (58.5%)	8.00 (4.65-13.89)	**0.000**	5.13 (2.35-11.16)	**0.000**
HIV Clinic attended [a]						
Lacor (faith-based hospital)	164	50 (30.5%)	1.00		1.00	
Others (GNRH and TASO)	304	131 (43.1%)	1.73 (1.16-2.58)	**0.008**	3.67 (1.79-7.54)	**0.000**
On HAART [c]						
Yes	231	87 (37.7%)	1.00			
No	236	93 (39.4%)	1.08 (0.74-1.56)	0.699		
HIV status of spouse [f, h]						
Negative	49	26 (53.1%)	1.00			
Positive	212	114 (53.8%)	1.03 (0.55-1.92)	0.928		
Disclosure of HIV status to spouse [f, i]						
Yes	267	128 (47.9%)	1.00			
No	60	27 (41.7%)	0.78 (0.44-1.37)	0.379		
Months since HIV diagnosis [j]						
Less than 24 months	215	81 (37.7%)	1.00			
24 months or more	247	99 (40.1%)	1.11 (0.76-1.61)	0.597		
Months on HAART [k]						

Table 3 Factors associated with current family planning use among PLHIV in Gulu District, Uganda, February-May 2009 *(Continued)*

Less than 24 months	111	37 (33.3%)	1.00			
24 months or more	119	49 (41.2%)	1.40 (0.82-2.39)	0.219		
Months attending HIV clinic [l]						
Less than 24 months	258	97 (37.6%)	1.00			
24 months or more	208	81 (38.9%)	1.06 (0.73-1.54)	0.766		
Complete PMTCT knowledge [a]						
Yes	315	133 (42.2%)	1.00			
No	153	48 (31.4%)	0.63 (0.42-0.94)	**0.024**		
Desire for children [m]						
Yes	184	72 (39.1%)	1.00			
No	246	100 (40.7%)	1.06 (0.72-1.57)	0.750		
Religion						
Other	128	51 (39.8%)	1			
Catholic	335	129 (38.5%)	0.95 (0.62-1.43)	0.792		
Spouses' desire for children (if married or de facto) [n]						
Yes	87	43 (49.4%)	1		1	
No	83	59 (71.1%)	2.51 (1.34-4.74)	**0.004**	2.19 (1.10-4.36)	**0.025**
Any HIV-infected children (among those with children) [o]						
Yes	75	38 (50.7%)	1			
No	223	97 (43.5%)	0.75 (0.44-1.266)	0.281		

AOR, adjusted odds ratio; CI, confidence interval; GNRH, Gulu National Referral Hospital; HAART, highly active antiretroviral therapy; OR, odds ratio; TASO, The AIDS Support Organization; [a] data for 8 respondents missing; [b] data for one person missing; [c] data for 9 respondents missing; [d] data for 7 respondents missing; [e] data for 19 respondents missing; [f] single respondents excluded; [g] data for 42 respondents missing; [h] data from 139 respondents missing; [i] data from 73 respondents missing; [j] data from 14 respondents missing; [k] data from 6 respondents missing; [l] data from 10 respondents missing; [m] data from 46 respondents missing; [n] data from 66 respondents missing; [o] data from 2 respondents missing

various organizations: personal barriers to using contraception, perceptions of family planning methods, decision making, covert use of contraception, targeting females for family planning services, and structural barriers to using contraception (summary in Table 4).

Personal barriers to using contraception

All the participants had heard about family planning methods but the majority were not currently using any method, consistent with the quantitative findings. Reasons for the low level of use included bad experiences with using some methods, fear of side effects, and health concerns. Some participants reported that for these reasons they would never use contraception again. It became clear that, after one bad experience, individuals often were reluctant to use alternative methods or took some time to do so. One female participant said:

"Yes. The injectable one, but it mistreated badly and I stopped it. I will never try again".

Another participant said:

"After I started using the drug I got side effect then I went back to the hospital and they told me to stop using it; I was using Depo injectable and they told me it was the one causing the side effect. And I have not used family planning method since then, but I want to go and start using another method if possible".

In some cases, there was spousal opposition to family planning methods. A female participant who was unable to use the contraceptive pill because of severe side effects was asked if her husband uses condoms and she responded:

"No, he doesn't allow to use them".

Some opposition was due to male concerns about experiencing reduced sensation while using the condom. One 40-year-old male participant said:

"Condom, I don't know how to use condom and you don't enjoy your sweet when it is wrapped".

For others, religious affiliation was an inhibiting factor for using contraception. One male participant said:

"He [the health worker] *advised me to use condom and other methods. And I told him I cannot use condom because I am a Catholic, and you can't control birth".*

Perceptions of family planning methods

Some clients had perceived family planning positively and they believed that family planning services helped families in a number of ways:

"I think their service is important because it helps a lot by reducing the burden on parents".

Opportunities to obtain advice on contraception were seen as important for both women and their children, as described by a female participant:

Table 4 Main themes from the semi-structured interviews with PLHIV in Gulu, Northern Uganda

Personal barriers to using contraception	Bad experiences with using some methods, fear of side effects, health concerns, and reduced sensation.
	Spousal opposition to family planning methods
	Religious affiliation
Perceptions of family planning methods	Positive perceptions
	Negative perceptions (among clients and health workers): • To condoms • To male vasectomy
Decision making	Male dominated
Covert use of family planning methods	Women surreptitiously receive injectables or implants at family planning clinics
	Clients keep the records at the health centre
Targeting of females for family planning services	Program managers mainly targeted females
	Men reluctant to do vasectomy but send spouses for sterilization
	Client perception that family planning was women's business
Structural barriers to using contraception	Lack of health workers trained in family planning provision and counselling
	Very few doctors in the region as a result of the civil conflict
	Only two family planning clinics based in Gulu town serving the whole population
	Male and female sterilization services delivered by Kampala-based medical staff
	Family planning services did not specifically target PLHIV
	No specific family planning programs for PLHIV in HIV clinics
	Lack of referral systems and lack of collaboration between health facilities

"Yes, I am advocating for the service to continue, because it helps people in spacing their children, therefore it helps in the proper growth of children and gives mother some resting period from one child to another".

Other participants perceived some methods as potentially harmful, a perception sometimes based upon misunderstanding or misinformation. One male participant said:

"There are some bad cases of condom because if you don't use it well you may lose one's life.... it can get stuck in the vagina... there are some coils used by women that can damage condoms".

UNFPA officials reported that male vasectomy was unpopular in this region. Some women believed that male sterilization would affect their husband's sexual performance, and some health workers were reluctant to recommend permanent methods to their clients:

"The health worker told me that child birth should be spaced but you should not be given a drug which will stop you from having children forever. You should use family planning so that you space your children and they will not be weak and sickly".

Decision-making

From the interviews with both men and women, it was apparent that males dominated in the decision making around fertility issues. While some female participants reported that they had discussions with their spouses about fertility and contraceptive use, ultimately the husband made the final decision. One female participant, who was interviewed after her husband, refuted his claim of using condoms to prevent more pregnancies:

"We always discuss this with him, but when he is drunk he reneges on what we have agreed together. ... That why I told you that we can decide on not having any more children, but when he drinks he changes his mind and start demanding for another baby, but his other family members don't like the idea".

A woman's reliance upon her husband to provide condoms even when she didn't want more children was another problem identified:

"I have never gone for one though I hear about, but we do use condom all the time and it is my husband who bring it. When he has forgotten, we just meet without it".

This comment reflects passivity and a lack of control or assertiveness over their own fertility that was found in several female participants interviewed.

Covert use of family planning methods

Some women preferred to use injectable forms of contraception because it allowed them to prevent further pregnancies without their husband's knowledge. The family planning service providers indicated that many women preferred to keep the records at the health centre so that their use of the services could be kept discreet. Attempts to use family planning covertly could result in severe consequences, as described by a family planning manager: A client's husband who detected implants she had surreptitiously received at a family planning clinic threatened to cut off her arm because she had unilaterally

made a major family decision, which he regarded was his to make. This attitude was further affirmed by a key informant:

'Once women are paid for at marriage, they do not have any say in the home. They are not expected to make any major decisions'.

Due to concerns arising from these attitudes, some women preferred contraceptive methods such as Depo provera where their husband would not need to know, and for which he would not have to give consent.

Targeting of females for family planning services

Program managers affirmed a low level of male involvement in family planning in general and admitted that their programs mainly targeted females, a feature which irked some men in the community. Several men told health workers that their programs would fail because they were targeting the 'wrong' people. However, there was a perception by some men and women that family planning was women's business. As one male participant said:

"They should provide women with information on the radio programme, and they organize meetings at the sub-counties where women are informed about family planning...not only wait when the women go to the hospital, but the health worker should come to the community and inform the women".

Family planning managers confirmed that while some men would send their women for sterilization, they were reluctant to undergo sterilization themselves. However, the covert use of family planning indicates that some female participants made unilateral decisions and accessed family planning without their spouse's knowledge and permission.

Structural barriers to using contraception

Based on the interviews with the family planning service providers, few health workers in Gulu were trained in family planning provision and counselling due to the inability of organizations to provide training services to health workers during the period of insurgency. According to the UNFPA officials, there were very few doctors in the region as a result of the civil conflict, and yet these were the cadre of health workers they preferred to train in surgical contraceptive procedures. There were only two family planning clinics based in Gulu town, run by Marie Stopes International Uganda (MSIU) and Reproductive Health Uganda (RHU), serving the whole population in Gulu and surrounding districts. Clients were mainly self-referred.

Most of the hormonal and barrier methods, except for the female condom, were available at these two facilities. However, male and female sterilization services were not provided directly at these clinics and were only available as part of mobile surgical clinics when medical staff could be deployed from the capital city over 300 kilometres away. These occasional outreach mobile services were unable to meet the needs of the PLHIV who wished to limit their family sizes. Overall, the family planning services provided to the general population did not specifically target PLHIV. Within the three HIV clinics, only TASO clinic provided counselling services and provided clients with free condoms. Thus, there was no systematic integration of reproductive health services in the HIV clinics, and there was lack of referral systems and collaboration between health facilities for family planning services.

Discussion

This study has documented the level of knowledge of, and factors associated with family planning use among a PLHIV population in the resource-poor, post-conflict region of Northern Uganda. We found a very low level of current family planning use despite a high level of knowledge about contraceptive methods. Factors associated with using family planning methods in this PLHIV population included having ever gone to school, discussion of family planning with a health worker or with one's spouse, not attending the Catholic-based clinic and spouse's non-desire for children. Discussion with a spouse have also been found to be associated with use of hormonal contraceptives in Rakai, Uganda [7]. Religion also has an impact on the uptake of contraception [14], through its influence at both the individual level and the institutional level, where faith-based health facilities may not directly provide family planning services to clients, thus limiting the access by PLHIV to these services.

Fear of side effects, reduction in pleasure, misinformation, negative perceptions, and gender-inequality have also been identified in other studies as barriers to adopting family planning [14-16]. As found in other studies [5,17], male sterilization was not used: Strong aversion to vasectomy has been linked to fear of male impotence in some societies [18,19], and/or reluctance to terminate males' reproductive career [14]. Our study also showed low use of dual methods of contraception among PLHIV. Use of a barrier method in combination with other contraceptives maximizes contraceptive efficiency and reduces the risk of HIV transmission to sexual partners [17].

PLHIV in our study who did not desire to have more children were often unable to access the family planning services they needed. The lack of association between desire to have children with use of family planning methods in this PLHIV population could be explained by the structural barriers that exist in Northern Uganda as a consequence of the long period of conflict in the region, which led to the outmigration of skilled health workers, the limited number of existing family planning clinics, and lack of provision of family planning services within the HIV clinics. The generally low level of contraception

use may be explained by the high level of desire for children in this population which may arise from esteem associated with large families [14], and low levels of female autonomy and literacy.

The strong desire to have children in this population may be further influenced by the prolonged civil conflict and high levels of infant and child mortality. Families, including couples living with HIV, which have lost their children during the conflict to either disease or violence, may have a strong desire to have more children. In societies with low literacy, endemic poverty, high child mortality and lack of social welfare and security programs, children are considered as a form of insurance to provide support in old age. Furthermore, having children in Uganda increases a person's social status [20] and this also applies to couples living with HIV.

Family planning programs and health workers mainly target women for family planning, but it is apparent that this approach did not result in discussion with their spouses or uptake of family planning services. Whether or not condoms were used was very much determined by the male spouse, particularly when the relationship was unstable. Our study showed that proportionally more females than males had discussed family planning with health workers. However, females generally reported not having discussed family planning with their spouse, whereas males reported high levels of spousal discussion on family planning, suggesting the focus of such discussions may have a different perspective for males and females. Fewer women than men reported using any method. Considering that men are the reproductive decision-makers in most traditional Ugandan homes [14], it is essential that reproductive health services also target men, educate them, and involve them in reproductive educational programs.

The ecological framework, as applied in this study, views the use of contraception among PLHIV as the outcome of interaction of factors at several levels: individual, interpersonal, and structural. At the individual level factors include demographic factors such as education status, sex, as well as personal attitudes and experiences of contraception. At interpersonal level, discussions and interactions with health workers, and spouses impact on the use of contraception. At the structural level, limited provision of family planning services in the general population and lack of integration of these services within HIV clinics inhibited the use of contraception among PLHIV. The usefulness of this framework is that it allows development of multi-level strategies to address the issue. Understanding the interdependency of factors at each level allows a holistic, and more effective approach to improving access while taking into account broader public health considerations.

Integration of family planning services with HIV services utilising a multi-level approach to improve the uptake is urgently needed in this region. Family planning programs should cater to PLHIV who wish to limit their family size, and also to those who wish to continue to have more children with a goal of achieving better health outcomes for the PLHIV through birth spacing and use of effective and safe contraception. Such integration has potential not only to improve reproductive health outcomes [21-24], but to ultimately reduce paediatric HIV infections [25], and hence reduce the amount of antiretroviral therapy needed. This is particularly important in countries such as Uganda where MTCT at 18% of new infections is a major route of HIV transmission [4].

Several levels of integration are possible. Family planning education should be provided within the HIV clinics and integrated into routinely provided general education programs with information on the effectiveness, safety, and possible side effects of all contraceptive methods. Doctors, nurses, and community workers attached to the HIV clinics could be trained in family planning counselling for PLHIV, and contraceptives could be provided free. Health workers can facilitate discussions of family planning with couples, either at health facilities or in the communities, and by doing so they can assist women in broaching the subject to their spouses and hence improve family planning use. HIV clinics have regular and prolonged contact with HIV-infected clients, and are ideally placed to meet their reproductive health needs over time [26]. While there has been some success in integration at PMTCT clinics [27], this is a temporary contact with HIV-infected clients that lasts only for the duration of pregnancy. Women generally do not return for post-natal family planning counselling [27], and PMTCT clinics target only women, whereas HIV clinics can target both men and women.

Family planning services can also be provided at the facility level, where clients are referred to separate clinics within the same health facility. It is also possible to have an active district-wide referral and follow-up service so that clients are appropriately referred to facilities that provide the service. Faith-based health facilities that may not directly provide family planning counselling and services can become part of a referral network. Although no difference was seen in this study between respondents' family planning discussions with health workers by the clinic they attended, actual use of family planning methods were significantly different, suggesting a need for active referral systems. Surgical contraceptive services should be readily available, sustainably funded, and provided by locally-trained doctors who could also deliver services at more remote clinics on a rotational basis. Nursing staff, in collaboration with community village health workers, could counsel and prepare clients for operations that are available on a regular schedule. The

suggested measures could be coordinated and implemented by the local district health departments in collaboration with health facilities, local community organizations, government agencies, and UN partners. Though possible constraints include lack of time due to large client numbers and commodity shortages, local government health departments could determine funding sources, training requirements and implementation strategies.

This is the first study on family planning use among a PLHIV population in a conflict/post conflict region and it adds to the literature on family planning use among male and younger PLHIV. The majority of previous studies have examined family planning use among women only. Information from females alone is insufficient, particularly in the context of a patrilineal and male-dominant society. By documenting use of family planning among males, their access to and perceptions of its use, a clearer and more holistic picture of why their spouses may or may not be using contraception is revealed. The sampling approach also ensured that the outcomes of interest (family planning use) could be assessed on adequate numbers of males and females in the different age groups as well as allowing statistical comparisons across sex and age groups. Additionally the combination of quantitative and qualitative methods has provided important information about the use of family planning methods. The quantitative findings provided us with information on the level of knowledge of and use of family planning among this PLHIV population and reveal the variables independently associated with the use of family planning. The qualitative data highlight gender inequality and limited access to and poor quality of available contraceptives as important contributing factors for the low use of family planning among PLHIV. The qualitative methods also allowed for exploration of additional concepts not captured in the survey questionnaire, such as covert use of contraceptives by women and targeting of women by family planning programs.

Limitations of this study include the cross-sectional design and, hence, causality cannot be determined. The non-random sampling and recruitment at the health facilities also result in a bias towards clients who are able to access health facilities, who are more urban-based or wealthier than those who had no access. The younger respondents aged 15-19 years and male respondents may have been more prone to positive health-seeking behaviours than their counterparts in the general population. Social desirability bias may have occurred when respondents were interviewed: PLHIV may feel that they have to indicate that they are using condoms to prevent further spread of the infection, especially if condom use has been previously promoted by health workers. While the ratio of males to females in this sample is similar to that in the general HIV population in Northern Uganda, caution needs to be exercised in generalizing findings to the general HIV population. Nevertheless, the findings provide important information about factors that are associated with use or non-use of family planning methods and, despite the unique complexities of this post-conflict region, may have implications for HIV populations elsewhere.

Future studies could consider comparison of HIV-infected with non-infected clients to determine the impact of HIV on access to family planning and its use. Research on the general PLHIV population is needed to measure unmet needs for family planning services among PLHIV. Interviewing couples separately to ascertain reported condom use is recommended for future research.

Conclusions

This study has documented a high level of knowledge but low use of family planning methods among a PLHIV population in post-conflict Northern Uganda, particularly among female PLHIV. Various individual and structural challenges prevent PLHIV from accessing the services they require. Integration of family planning services and education into HIV clinics could help ensure that these services become readily accessible to PLHIV and this would be a significant progress towards HIV prevention and reduction of HIV incidence in this post-conflict region.

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Authors' contributions

BN designed the study, collected and analysed the data, and prepared the initial draft. JL, SCT, CGO and JE assisted with the design of the study, and contributed to the interpretation of the results, reviewed the various drafts and assisted with the writing. All authors have read and approved the final manuscript for submission to a peer reviewed journal.

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Competing interests

The authors declare that they have no competing interests.

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7.6 Summary of the Chapter

This chapter presented the knowledge of, access to and factors associated with family planning services in Gulu, Northern Uganda and also suggested a model to improve access to family planning services in this region. The next chapter draws the conclusions of the whole thesis, and discusses the overall factors influencing the desire to have children in the PLHIV in Gulu.

CHAPTER 8: DISCUSSION, CONCLUSIONS, SIGNIFICANCE AND RECOMMENDATIONS

8.0 Introduction to the Chapter

This chapter commences with an overview of the research design. This is followed by a discussion of the findings from the preceding chapters on the desire to have children among PLHIV, experiences of stigma and its impact on the desire to have children, and the use of family planning methods among PLHIV in Gulu. The chapter provides recommendations, and it ends with a discussion of the significance of the study, the limitations of the study and a final concluding statement.

8.1 Overview of the research design

Desire to have children among PLHIV is complicated and the decision-making process around having children in the future is influenced by a multitude of factors. Therefore, a mixed-methods design was used in order to answer this question holistically. The quantitative survey was designed to provide information on the proportion of PLHIV who wanted more children, were using family planning, perceived that they were stigmatised and the factors that were associated with these outcome variables. In isolation, the survey research would have been unable to offer much in providing the answers to these questions and interpreting the findings (Greene, Benjamin, & Goodyear, 2001). For example, the survey did not provide insight into why proportionally more men desired children, why the female participants were not using contraception, or highlight the worries that PLHIV had around infecting their own children with HIV. The qualitative component of the study offered insights into the processes of stigmatisation and fertility decision-making, together with the use of family planning methods among this population. Therefore, the qualitative data provided more in-depth knowledge about the life experiences of PLHIV.

The purpose of the mixed methods approach, with separate and concurrent qualitative and quantitative data collection, was to compare and triangulate the results and to corroborate the findings. The combination of these two methods

allowed a better understanding of fertility desires, family planning use, and stigma experiences among PLHIV in Northern Uganda. This complementary feature of the study methods has deepened our understanding of the issues by enhancing completeness of the data, providing the context for interpreting the research findings, and offsetting the weakness in one approach with a more nuanced understanding provided by the other (see Table 18).

Completeness

In this study, the qualitative data highlighted important gaps in information obtained using the quantitative methods. For example, the qualitative methods revealed important themes not covered in the questionnaire, such as structural barriers to contraceptive use, covert use of contraceptives by women and targeting of women by family planning programs. These themes explained why only a small proportion of PLHIV reported to be using family planning services despite their knowledge about how to prevent further pregnancies, and also how women managed their reproductive careers. These qualitative methods also revealed that family planning programs inadvertently targeted women, many of whom were not able to make unilateral family planning decisions. The findings thus explained why there had been low uptake of family planning services in this region and provided evidence for recommending policies such as integration of family planning services with HIV services, couple counselling and targeting of men in order to enhance use of the family planning services among PLHIV.

Explanation of findings

The qualitative findings also provided insight into some of the statistically significant associations found in the quantitative data. The quantitative data showed that more male participants were using contraceptive methods than females. Semi-structured interviews revealed that men were not using family planning methods as frequently as they reported. Men held the power in decision-making; therefore, when they wished to use contraceptives, they had the power to act upon it. This was not the case for many women who were often unable to negotiate contraceptive use. Similarly, the qualitative information suggested that the positive association between discussion with the spouse about family planning and actual use of contraceptives as found in the quantitative data may have been a proxy for having the husband's permission to

use contraceptives. Together these findings illustrated the strong patriarchal influence on female reproductive behaviour in this region. This knowledge can be used to shape future interventions that seek to assist PLHIV in meeting their reproductive needs.

Providing Context

One of the most important contributions of the qualitative arm of the study was to provide contextual information about desires for children among PLHIV. This method enhanced understanding of the cultural context in which PLHIV made decisions to continue to have children despite their HIV status and the risk of infecting their children. Based on the study's quantitative findings, significantly more males than females (54.2% males vs. 31.7% females) desired to have more children. Furthermore, of the 246 participants who said they did not desire to have any more children, 59.3% were not using any form of contraception: 34% of the 97 men and, significantly, 76% of the 148 women, who reported they did not want any more children, were not using any form of contraception. The qualitative findings revealed that some women were unable to prevent unwanted pregnancies and could not determine whether or not they stopped having children despite their wishes not to have any more. In fact, some women who wanted to use family planning methods had to use covert measures to limit their fertility. The context in which PLHIV made these decisions was critically important as it enabled a better understanding of the fertility desire and utilisation of family planning methods and services in this PLHIV population.

Offsetting

Some studies use mixed methods because the weaknesses of one method can be offset by the strengths of another (Tashakkori & Teddlie, 2003). For instance, the survey mainly consisted of forced-choice questions where respondents could only choose from a range of answers. One of the key constructs in the quantitative arm of the study - fertility desire - was measured using a single item with a binary response. The study participants were expected to answer 'yes' or 'no' to the question of whether they would like to have any more children. The qualitative data revealed that fertility desires among PLHIV and its impact on behaviour were more complex than what the single item question with binary answers could capture. Issues of sexuality,

HIV and reproduction are highly sensitive and in some contexts may generate inaccurate responses or no response. Forced-choice questions may also generate inaccurate responses. Unlike the structured interview, the qualitative interviews were able to explore this issue extensively and in a culturally-sensitive way. These questions were easier to ask and explore during the qualitative interviews which were carried out in the familiar surroundings of the participants' homes and after development of trust and rapport between the interviewers and participants.

Table 18: Examples of complementary features of the methodological approach of this study

Quantitative findings	**Qualitative findings**	**'Pragmatic' explanation of issues raised**
Men report higher usage of contraception than women	Some women report men are inconsistent with family planning; not truthful in their responses	Explanation: There was response (social desirability) bias in information reported by men to interviewers. Women are disempowered and over-ruled in matters of safe sex and family planning by their male partners and his family
High level of desire to have children in this PLHIV population: 43% of total, 54% of men and 31% of women (significant difference by sex)	High importance is attached to marriage and child-bearing in this strongly patrilineal society. Some men are concerned with perpetuation of lineage while women are concerned with personal health and HIV transmission concerns	Context: Women are unable to make unilateral decisions on intent to have children in the future. There are strong cultural factors influencing couples to have children

Quantitative findings	Qualitative findings	'Pragmatic' explanation of issues raised
76% of women who do not desire to have children are not accessing the family planning services they need	Women are relying on their spouses to provide contraception or are using covert methods when they can access the services	Context: Women are unable to make unilateral decisions on intent to have children in the future
Low use of contraception in population, only 38% reported to be using contraception	HIV clinics are not directly providing family planning services, with only two clinics serving over 500,000 people in Gulu District. Family planning programs are mainly targeting women and not men or couples. There are also personal objections to use of family planning	Explanation/Completeness: the qualitative findings explain the low use of contraception i.e. the barriers to use of contraception including cultural, structural and personal factors

8.2 Desire to have children among PLHIV in Northern Uganda

The participants for this study were drawn from Gulu and the surrounding villages. In total, 502 PLHIV participated in this study. Largely a rural population, most of the participants were not highly educated, many were peasant farmers and housewives, and most were of the Roman Catholic faith. An equal number of males and females were interviewed and also an equal number of participants from each age group were selected to allow comparisons by sex and age-group. About half of the participants were married or in de facto relationships and some were also in polygamous relationships. The majority of the participants had children and the median number of children was three. Just fewer than eight percent of the female participants were pregnant at the time of the study.

There was a high level of HIV knowledge among the participants, with many knowing where to access HAART and PMTCT programs. The majority of the PLHIV had known their HIV status for over two years, had been attending the clinic for over two years and half of them were accessing HAART at the time of the study. Of note is that compared to male participants, proportionally more female participants had known their status for longer, had been attending the clinic for longer and more of them were on HAART. Not all participants had discussed their HIV status with their spouse and this was more so for the female participants. In addition, 18.7% of the participants did not know the HIV status of their children. This is a significant proportion because if the children have HIV infection, it means that they are not accessing the essential HIV care services.

Drawing the qualitative and quantitative data together, there was a high level of desire to have children among this PLHIV population. Forty three percent of the participants said they still wanted to have children, including 54% of the male PLHIV and 32% of the female PLHIV. This high level of desire among the PLHIV in Northern Uganda was in marked contrast to four other studies done in other regions of Uganda, which have shown low levels of desire to have children among PLHIV. Heys et al. (2009) reported that only 14% of male and female PLHIV in Kabarole in Western Uganda wanted more children. Similarly, Nakayiwa et al. (2006) reported that only 18% of male and female PLHIV in their study conducted in Jinja, Eastern Uganda, wanted more children. Maier et al. (2009) found only 14.6% of female PLHIV in Mbarara desired to have more children and Homsy et al. (2009) found less than 7% of female PLHIV in Tororo and Busia, wanted to have more children.

The marked difference in desire to have children between Northern Uganda and other regions in Uganda could be explained by the long-term conflict in Northern Uganda and associated high levels of infant mortality. As earlier explained in the Methodology Chapter, Northern Uganda had very high levels of infant and under-five morbidity and mortality secondary to AIDS, tuberculosis, malaria and other communicable diseases during the 20-year insurgency (Accorsi, et al., 2005; Ministry of Health Uganda, 2006; Uganda Bureau of Statistics & Macro International Inc, 2007; World Health Organization & Ministry of Health Uganda,

2005). However, only a comparative study would be able to confirm this as the reason for the significant difference between the desires to have children in this region in comparison to other regions in Uganda.

The quantitative findings showed that a significantly higher number of men were interested in having more children in comparison to women and this was confirmed and explained by the qualitative findings. This significant association of male sex with a greater desire to have children among PLHIV was also found in other studies conducted in Uganda (Heys, et al., 2009; Homsy, et al., 2009; Nakayiwa, et al., 2006) and elsewhere (Myer, Morroni, et al., 2007; Paiva, et al., 2003; Santos, et al., 1998). The desire to have children in this study was also significantly associated with marital status and spousal desire to have children.

Unlike other studies, the desire to have children did not remain significantly associated with age, number of living children and death of a child. The lack of association between age of participant and number of children with the desire to have children was an unexpected finding. It was only in the Peltzer (2008) study that desire for more children was not associated with number of living children and in Sowell (2002) study where age was not associated with the desire to have children among PLHIV. Though these factors were associated with the desire to have children on bivariate analysis, this effect was lost after multivariate analysis. This was probably due to the strongly significant relationship with the other factors including spousal desire, sex and marital status. In the semi-structured interviews, the desire to have children was further influenced by the desire to fulfil family and societal obligations, spousal influences, their desire to have heirs, concerns about the children's future and their potential infection, and availability of HAART and PMTCT programs. These factors were also reported as impacting on the desire to have children in other countries (Nattabi, et al., 2009).

The qualitative findings revealed that though the female participants were aware of the importance of children in their society, and saw children as a source of joy and help, many were concerned about their own health, as well as possible infection of their children. Male participants, while also concerned about possible infection of their children, were particularly influenced by the societal expectations of having

children in their society and wanting to meet these expectations. As discussed in Chapter 3, having children is a milestone for many people in Sub-Saharan Africa and like other people, PLHIV strive to meet their kinship and social obligations. This study found that the male participants were also interested in accessing HAART and PMTCT programs and some proactively took their spouses to attend the necessary services. The male participants were more concerned with heirs and inheritance than the female participants. The quantitative findings showed that more female participants had experienced the loss of a child, and this may explain the lower desire to have children among women.

Pressures from spouses and family members had a strong influence on the desire to have children among both male and female participants. Some PLHIV felt that they had to meet their spouses' need to have children. From the quantitative data, spouses' desire to have children remained significantly associated with the desire to have children among the participants, after controlling for other factors. Some family members had high expectations for PLHIV to have their own children, while others did not want the PLHIV to have more children in case they gave birth to HIV-infected children.

Though the quantitative arm of the study did not investigate how many participants had had children after their HIV diagnosis, the qualitative arm found that 31% (8/26) of the participants had had children following their HIV diagnosis. As described, some participants were able to access the PMTCT and HAART services, and for some a healthy infant without HIV was the outcome. Some participants were apprehensively waiting on their results. Overall, there was concern about potential infection of children, and participants were particularly happy that HAART and PMTCT could increase their chances of having HIV-negative children.

Accordingly, the ecological framework, as used in this study, proposes that no single factor can explain why some PLHIV desire to have children in the future and others do not. This framework views the desire to have children as the outcome of the interaction of factors at four levels, that is, individual, interpersonal, community and structural levels:

- At the *individual* level, there are personal, historical and biological factors that influence the desire to have children among both male and female PLHIV. These factors include age, sex, number of children, and feelings of internal stigma.
- At the *interpersonal* level, pressures from spouses and family members, as well as gender roles influence PLHIV's desire to have children.
- At the *community* level, the levels of stigma expressed by other community members, the social norms of men and women and their social obligations to their community may influence the desire of PLHIV to have children.
- *Structural* level factors include HAART and PMTCT programs.

The usefulness of this framework is that it allows the development of strategies that would address the desire to have children, family planning and reduction of stigmatisation in a multi-layered approach. It is important to understand the multi-factor and multi-level and interdependency of factors or influences on individual behaviour. This in turn allows a holistic, more comprehensive and more effective approach to developing solutions to health problems. The importance of multi-level, including structural, interventions cannot be over-emphasised. Individual-based approaches that only rely on changing behaviour, for example through education, or the provision of information and counselling, do not produce optimal results as long as factors influencing behaviour at structural, social and environmental levels remain unaddressed (McLeroy, et al., 1988; Sweat & Denison, 1995).

Equally important, however, are even higher superstructural level factors that impact on the ability of women in Sub-Saharan Africa to make important reproductive decisions. Superstructural factors are higher level social justice factors that shape the experiences at every other ecological level and include factors such as class, poverty, racism and other forms of discrimination (Scott & Wilson, 2011). Earlier in Chapter 2, 'drivers' of the HIV epidemic were discussed in detail and how they impact on the spread of the HIV epidemic. The term 'driver' relates to the structural and social factors, such as poverty, gender inequality and human rights violations, that are not easily measured but that increase people's vulnerability (UNAIDS, 2007b). Fertility desires in Sub-Saharan Africa are also influenced by superstructural factors or

'drivers', such as poverty, low levels of education, particularly among women, and gender inequality. The long-standing civil conflict in Northern Uganda is another superstructural factor which led to the extremely high levels of poverty in Northern Uganda and high infant mortality rates. In addition, the enormous social pressures for women to reproduce, and the shame associated with lack of children, are also 'drivers' of the desire to have children among women on the continent, including those living with HIV. Unfortunately, in the case of the latter, there is a possibility that they could infect their infants with a debilitating and fatal infection.

In summary, the decision-making process around having more children among PLHIV in Gulu was highly complex, taking into account many social and cultural pressures at community and familial level and their own desires and views. Many of the participants had reassessed their ability to have children and to look after them. Though there was generally male dominance in decision-making around fertility, some female participants were taking unilateral decisions to halt childbearing by covert use of contraception. Many of the participants, particularly the males, were concerned about future heirs and inheritance of their property. This is not surprising considering it is a strongly patriarchal society with high expectations that men and women should have children. Therefore, the desire to have children was affected by a multitude of factors which included sociodemographic factors, cultural expectations, stigma-related issues, access to HAART and PMTCT, personal health concerns and spousal and family pressure to have or not have children.

8.3 Experiences of stigma among PLHIV in Northern Uganda

Despite the fact that the HIV epidemic has lasted more than three decades, stigma continues to impact on the quality of life of PLHIV in Northern Uganda. Verbal abuse and internal stigma were the main forms of stigma experienced by PLHIV in Gulu. Females, older participants and those who had been on HAART for a longer time experienced higher levels of perceived stigma; female participants particularly had higher levels of internal stigma. The study also revealed that HIV-related stigma had an impact on fertility desires through various mechanisms. For example, stigmatising behaviours such as verbal abuse and desertion led to decreased desire to have children. Family, community and health workers either mitigated or enhanced stigmatisation of PLHIV, leading to increased or decreased desire to have children,

respectively. Thus stigma remains one of the most important factors influencing desire to have children among PLHIV.

This study also found that the relationship between HAART and stigma is complicated. Wilhelm-Solomon (2010) found that the lack of confidentiality in service delivery could partially explain the relationship between HAART and increased level of stigma in Northern Uganda. This could explain the higher levels of stigma among the participants who had been on HAART for longer, as found in the quantitative arm of the study. In contrast, the qualitative arm of the study revealed that HAART, by reducing debilitating signs and symptoms of the disease and improving the quality of life of PLHIV, could also lead to reduction in both internalised and received stigma. Therefore the role of HAART in reducing or increasing stigmatisation of PLHIV depends on the context and this should be carefully considered by health workers and program managers who deliver these services to PLHIV.

It is important therefore, that measures are taken to reduce personalised and community expressions of stigma, as this remains a major public health problem. PLHIV need to be able to make fertility decisions without the burden of stigma from either internal or external sources. It is important for health systems to be accessible to assist PLHIV access the care and support they need to prevent further spread of HIV to their infants and loved ones.

8.4 Family planning use among PLHIV in Northern Uganda

Studies on family planning among PLHIV worldwide have found a range of methods used and a variety of factors associated with its use. The importance of the availability of family planning services cannot be over-emphasised; nevertheless, it is important to understand the factors associated with the use of family planning services, because knowledge about and availability of services do not automatically translate into use. This study has documented the high level of knowledge of, but very low-level use of, current family planning among PLHIV in Gulu. Family planning use among PLHIV in this region was markedly lower than in other regions in Uganda. Other Ugandan studies showed significantly higher levels of family planning use among PLHIV with up to 85% of female PLHIV in Mbarara (Andia, et

al., 2009) and 74% of PLHIV in Kabarole (Heys, et al., 2009) using contraception methods compared to only 38% of this population. In a more recent study that compared PLHIV attending 12 HIV clinics across Uganda, Wanyenze et al. (2011) also reported that women in Gulu were the least likely to be using modern methods of contraception, in comparison to PLHIV from clinics in other parts of Uganda. Also noteworthy is the significantly higher proportion of male participants using contraception compared to female participants. Despite the high levels of condom use among the male participants, condoms are not an effective form of contraception. Where appropriate, dual contraception needs to be encouraged to prevent re-infection as well as pregnancies for PLHIV who wish to delay or stop having children.

Factors associated with use of family planning methods in this PLHIV population included having ever gone to school, discussion of family planning with a health worker or with one's spouse, not attending the Catholic-based clinic and spouses' non-desire for children. Similar to other studies (Nakayiwa, et al., 2006; C. Polis, et al., 2009), respondents' education in this study was associated with family planning use. This study found a lack of association between an individual's desire for children and the use of family planning methods, unlike the study by Andia et al. (2009) in Mbarara. The association between spouses' desire for children and reduced use of family planning as found in this study, was also significant.

As discussed by Nattabi et al. (2011b), the lack of association between desire for children and use of family planning could be explained by the structural barriers that exist in Northern Uganda following the long period of conflict in the region. PLHIV in this region who did not desire to have more children, particularly women, were not able to access family planning services. Factors at both the interpersonal levels (e.g. spousal desire for children) and structural levels (availability of services) contribute to this discrepancy. Strong patriarchal influences prevented some women from making decisions on the use of contraception, and those who were determined to control their family sizes used covert methods. Family planning services in this region have been targeting women, but this has not led to improved uptake in the population. Thus the multi-level interventions as discussed in the article were aimed at overcoming these barriers, so that the PLHIV in this region could also meet their

reproductive needs and ultimately reduce the high prevalence and incidence of HIV in the region.

It is important that program managers who are concerned with promoting family planning recognise that gender and family dynamics may prevent some women from accessing the services they need and power imbalances in the home may put women at risk of domestic violence as they try to access these services. Thus gender inequality will impact on the woman's ability to access services. For this reason, a couple-approach and interventions at a structural level are very important to improve family planning uptake in such a society. As Ezeh (1993) stated "...a program that targets men as a means of reaching and altering their wives' reproductive behaviour will fare much better than one that targets women as a means for reaching their husbands". Therefore, the approach to service provision should change to better support PLHIV couples and their families.

8.5 Recommendations from the study

The findings of this study provide information that can be used in the post-conflict improvement of HIV care services and programs in Northern Uganda. The paucity of information during the 20-year long conflict limited the development of HIV programs in Northern Uganda, particularly evidenced-based programs. The recommendations below can be adapted by local HIV program managers, ministry and district health officials, and other organisations that support programs in the region. The recommendations are broken down into three main sections: 1) the desire to have children among PLHIV, 2) provision of family planning services, and 3) the reduction of stigmatisation of PLHIV in Northern Uganda. However recommendations for more structural level interventions will also be suggested with an aim to improve the ability of women and girls in Northern Uganda to determine their own reproductive and health future. Recommendations for future research are also suggested.

8.5.1 Support for desire to have children and decision-making processes among PLHIV

Health workers and program managers should understand the context in which PLHIV make decisions around future reproduction as some PLHIV want to have

more children, others do not want more children, while other PLHIV want to wait a while. Health systems should be able to support PLHIV through the decision-making process, and allow them to make informed decisions. Particularly health workers should discuss the risks of and timing of MTCT transmission of HIV with PLHIV who wish to have children in the future, and counseling should be tailored according to the stage of HIV infection, and whether or not the PLHIV are on or plan to start HAART. Therefore, doctors, nurses and counsellors should be trained on how to assist PLHIV through a planning process so that those who need HAART and/or PMTCT to improve the outcomes for their children can access these services. It is therefore recommended that:

a. Health workers are educated and develop an understanding around the desire to have children among PLHIV
b. PLHIV are supported by health workers and program managers to make informed decisions around future reproduction
c. PLHIV have access to services that prevent transmission of HIV from mother to child i.e. HAART and PMTCT, so as to reduce the number of infants being infected in the region

8.5.2 Improvement in utilisation of family planning services in Northern Uganda

To cater to the needs of those PLHIV who wish to wait or those who want to terminate their reproductive careers, there needs to be integration of family planning services with HIV services utilising a multi-level approach to improve the uptake. Integration would include:

a. Providing family planning education within the HIV clinics
b. Training doctors, nurses, and community workers in family planning counselling for PLHIV
c. Training local doctors in surgical contraception procedures
d. Setting up a referral system between the health facilities for clients to access care across the district given that family planning services may not be directly offered within some facilities
e. Educating and supporting males in family planning to improve uptake of family planning services

f. Special consideration for adolescents (clients aged 15-19 years): programs tailored for this age group should be developed in order to enhance their utilisation of HIV prevention and curative services. Their specific needs regarding family planning need to taken into account when developing services for the PLHIV population.

8.5.3 Reduction of stigma among PLHIV

There is need for development of multi-level interventions in the region to reduce stigma targeting individuals, the health system and communities. It is recommended that interventions target:

1. Individual PLHIV

a. Development of individual's skills in management of disclosure of HIV status

Disclosure is an important element in the management of stigmatisation and has been found to improve healing, empower and relieve PLHIV from the burdens of secrecy (Sandelowski, et al., 2004). Disclosure of HIV infection will depend on whether it would lead to positive outcomes in the form of support or whether it would lead to increased stigmatisation of the individual. One of the major benefits of disclosure is increased support from family and the community, and PLHIV should be encouraged to disclose, albeit, in a strategic, measured way. Counsellors should teach PLHIV how to frame, and time, disclosure in order to minimise stigmatisation and maximise positive outcomes. Counsellors could also assist PLHIV in deciding to whom to disclose their HIV infection and whether they should include health workers and important family members who can provide support. Correct timing of disclosure is essential and it should take into account whether the person is ready and can cope with the varying outcomes of the disclosure process. The content of disclosure is also important and includes the stage of the disease and medications taken. Sandelowski (2004) suggested that certain rules need to be taken into account including a need to know, a capacity or readiness to tell, and low psychological and social risks to themselves and to those being told.

b. Creation of PLHIV peer groups to mitigate stigma and provide support

PLHIV in Gulu should be encouraged to join peer groups where they can receive support from other PLHIV. In such groups, PLHIV can feel normal as there is more

acceptance and relief from internalised and overt stigmatisation (Alonzo & Reynolds, 1995). Medley et al. (2009a) found that PLHIV in Uganda received a lot of support from PLHIV groups with feelings of solidarity. They could share coping strategies, instead of using those suggested by people who may not have had similar experiences. Encouragement of individuals to join networks of PLHIV would assist in helping them cope and find other forms of support outside their family and the health system. PLHIV should also be encouraged to obtain the necessary training and qualifications in order to work in HIV prevention and curative services as health workers, community workers, counsellors, and managers of PLHIV services. These jobs will enable PLHIV to support their families, will lead to increased self-reliance and enhanced self-esteem. PLHIV working within HIV curative and preventative services will also ensure that these programs are properly tailored to their needs.

c. Cognitive Behavioural therapy programs

Cognitive behavioural therapy (CBT) has been found to reduce internal stigmatisation and stress, improve self-esteem and help PLHIV cope with their illness (Heijnders & Van Der Meij, 2006). In this approach, patients are trained to modify and challenge negative beliefs and thought processes. PLHIV in Northern Uganda, especially women, would benefit from a reduction in self-stigmatisation, and an increased ability to cope with their HIV-positive status. A related approach which has been shown to benefit PLHIV is emotional writing disclosure (EWD), a technique developed for people suffering stigmatisation due to various conditions including HIV/AIDS (Abel, Rew, Gortner, & Delville, 2004). This approach has been shown to result in cognitive reorganisation with secondary outcomes such as improved adherence behaviour, as well as psychological and physiological health benefits. PLHIV living in Northern Uganda could also benefit from this technique, although it would have to be modified for those who cannot read and write. It is possible a verbal technique could assist this group of people.

2. The health system

a. Health workers education on stigma and its impact on utilisation of health services among PLHIV

Though most health workers in Uganda are knowledgeable about HIV, it is important that they are educated about the effect of their attitudes and actions on the utilisation

of services by PLHIV. Their negative attitudes and behaviour deter PLHIV from accessing services early in the course of their illness, while positive attitudes by health workers make it more likely that PLHIV will use services and be cooperative. Counsellors could also train health workers on how to handle PLHIV with sensitivity and understanding in order to improve the uptake of the services by PLHIV. It is important to emphasise that health workers' attitudes and behaviour ultimately have an impact on further spread of the infection.

b. Re-organisation of health facility HAART provision to reduce the impact of stigma on PLHIV accessing health facilities

Health administrators need to consider changing aspects of HIV care delivery that enhance stigmatisation of PLHIV, for example the layout of the clinics, and identifiers on client's charts. Confidentiality policies also need to be devised to protect the privacy of PLHIV.

3. The Community

It is vital that the community is educated on the routes of HIV transmission and that myths about HIV transmission are debunked. The community also needs to be educated about the treatment available in the region, including the availability of VCT, HAART and PMTCT programs. This information can be communicated via media outlets (radios and TV), as well through community events and support groups. This social marketing will enable community members to be aware of the services in the district, and the role of PMTCT and HAART in prevention and treatment of HIV infection and how to access these services for themselves and their family members. Overall this would lead to a reduction in community stigma and improvement in quality of life of PLHIV.

8.5.4 Education of women and girls

Most of the recommendations above are targeting the practical issues of delivery of HIV and family planning services. However, there also needs to be a fundamental change to the way women are culturally viewed and view themselves in order to address upstream influences on the desire to have children. These changes will take a long time but they start with the education of women and girls in Northern Uganda. High levels of poverty and low status of women and high illiteracy levels impact on

female autonomy including their ability to decide on fundamental health issues. Education, economic and social empowerment of women and fundamental cultural change will allow them to have more choices and reduce the need to have their social status tied to the number of children they can produce. For this purpose, empowerment will be defined as "a multidimensional process of change from a position of disempowerment…in which individuals are active agents and shaped by the context…and must be sensitive to the context in which women live" (Murphy-Graham, 2010). Since empowerment cannot be imposed by external agents and is self-driven, interventions to 'empower' women must provide an enabling environment (self-enhancing tools and other support systems) where women can develop the ability to make decisions and exert control over their lives (IPPF, UNFPA, & Young Positives, 2007).

It is essential that women are empowered within their intimate relationships so that they are able to negotiate and influence the nature of these relationships and the decisions made within them (Murphy-Graham, 2010). Many interventions and much research have looked at the empowerment of women in the public sphere and reported that sometimes a woman's education and or access to resources may not have an impact on her ability to influence decisions in her private sphere. Therefore, education of women alone cannot empower women unless it ensures transformation of unjust relationships and values. True empowerment ensures that women are able to fully understand how gender relations influence the fortunes of men and women and how these relations can be changed, and also gain interpersonal skills (negotiation, communication skills), and access to material resources (Murphy-Graham, 2010). As Murphy-Graham (2010) stated "empowerment is a process through which women come to recognize their inherent worth…and begin to participate on equal terms with men to dismantle patriarchy and promote social and economic development" (p. 321). Through empowerment of women in Northern Uganda, gender equality can be reached where both men and women can reach their full potential. Only structural changes to the way societies undervalue women and girls and a cultural reform can enable women to negotiate their place in society, for the betterment of their health, children and ultimately that of the communities in which they live. A cultural reform will enhance those aspects of Sub-Saharan African

culture that enable the society and a reassessment of those aspects of culture that undermine vulnerable segments of the society.

8.5.5 Future research

This study was not able to examine all factors that impact on the desire to have children, family planning use and stigmatisation of PLHIV in Northern Uganda. Further studies could look more extensively at structural factors and policies that impact on these outcomes. This study also did not extensively examine the impact of the civil conflict on fertility desire and the level of HIV-related stigma. Future comparative quantitative and possibly ethnographic and anthropological studies could determine the causes of the marked differences in desire to have children and family planning use between PLHIV in this post-conflict region and other regions in Uganda and possibly if there are differences in stigma levels experienced by PLHIV. In addition, future studies could examine HIV and reproductive health care needs among men. Several studies have documented that male attitudes and practices impact on their spouses' ability to access health care (Skovdal, Campbell, Nyamukapa, & Gregson, 2011) as well as their own access to health care (Skovdal et al., 2011). Detailed examination of their engagement with health services and what their needs are could highlight gaps in programming for which appropriate and effective interventions could be developed. As this study did not compare HIV-infected with non-infected populations, future studies could consider comparison of HIV-infected with non HIV-infected clients in this region to determine the impact of HIV on access to family planning and its use, as well as fertility desires. Research could also be conducted on the general PLHIV population to determine unmet needs for family planning services in this region.

8.6 Significance of the study

This study was the first of its kind in post-conflict Northern Uganda. Though various studies on fertility desires have been carried out in Uganda and elsewhere, it was important for this study to examine the desires of PLHIV to have children in this part of Uganda, given its unique context of war and civil conflict for the previous 20 years. The study provided insights into the fertility desires of HIV-infected men and women from urban, semi-urban and rural areas. It has contributed to the discourse about HIV-infected men, their desires and the influence that they have on their

spouses' fertility and contraception choices. Many of the other studies on desires of PLHIV have concentrated mainly on women. This study explored the desire of both male and female PLHIV to have children, and this is especially important in a strongly patriarchal society like Northern Uganda.

The mixed-methods approach, the pragmatic paradigm selected, and the use of the Social Ecological Framework as the overarching framework for this study were also of great significance. All of them allowed the multi-factor and multi-level analysis of this phenomenon in order to understand the complexity around the desire to have children among PLHIV. The study can be considered significant on the basis that the findings:

(i) provided information on the fertility desires of both HIV-infected men and women in a post-conflict setting;

(ii) identified contextual factors that influence reproductive decision-making among both HIV-infected men and women, so that culturally-appropriate interventions could be recommended;

(iii) provided information on the programmatic needs of the respondents based on the identified fertility desires - for example, HAART, PMTCT programs, counselling and support and family planning programs; and

(iv) elicited information on how family planning services for HIV-infected people could be further integrated with HIV prevention and care services in Northern Uganda.

8.7 Limitations of the study

This study has several limitations, including its cross-sectional design which prevents causality from being determined. In addition, monetary and time constraints limited recruitment to the three health facilities, which could have resulted in a bias towards clients who were able to access health facilities because they were urban-based or wealthier than others. We tried to reduce this form of bias by recruiting some respondents from the outreach clinics attached to Lacor hospital and TASO clinics. Social desirability bias may have occurred when respondents were interviewed by the nurses. PLHIV might have reported that they were using condoms to prevent further spread of the infection, especially if condom use and contraception had been previously promoted by health workers. PLHIV may have also indicated that they

did not desire to have children to remain socially acceptable, considering that most of them would know that there was a possibility that they could infect their children with the virus. However the use of nurses as interviewers could not be avoided as they had access to the clinics and clients and were deemed capable of filling in the questionnaires.

Quota sampling ensured that the ratio of males to females in this sample was similar to that in the general HIV population, and allowed comparison for the outcomes of interest. However, caution needs to be exercised in generalising findings to the clinic population or the general HIV population because of the non-probability sampling technique. Finally, although having lived in the region for ten years, the researcher had only a basic understanding of the language in which the interviews were conducted because it was not her first language. As a result, she had to rely on the local interviewers to collect data on her behalf. Though the interviewers translated the qualitative interviews, some important information might have been lost or not given appropriate emphasis in the translation. Lack of a firsthand, in-depth understanding of the language in which the interviews were conducted could have led to loss of important data. For instance, the interviewers may have interpreted the data on behalf of the researcher which could have affected the data analysis. Though the researcher held daily discussions with the interviewers to reduce the likelihood of this happening, this could have affected the themes developed from the data.

8.8 Final Concluding Statement

This study came about as a result of my interest in the fertility desires and intentions of the PLHIV at the clinic where I worked for over five years. Pregnancy and the desire to have children among PLHIV have been problematised for many years but this study confirms that the desire to have children among PLHIV is affected by a multitude of factors. Using the Social Ecological Framework, this study showed that the desire to have children was the outcome of interaction of factors at four levels: individual, interpersonal, community and structural. At the individual level, there were personal, historical and biological factors that influenced the desire to have children among both male and female PLHIV. Most important among these factors was sex of the respondent, marital status and feelings of internal stigma. At the

interpersonal level, spouses' desires, pressures from family members, and gender roles were the most important factors that impacted on the desire to have children among PLHIV. At the community level, the factors that impacted on the desire to have children included the levels of stigma expressed by other community members, cultural factors like the social norms of men and women and their cultural obligations to their community. At the structural level factors that impacted on the access to health services also influenced the desire to have children among PLHIV. These included the long civil-conflict that reduced access to family planning, PMTCT and HAART programs. Superstructural level factors included gender inequality, low levels of education and high levels of poverty.

Furthermore, this study has been a personal journey for me. When I sat in front of the pregnant HIV-positive client many years ago, I realised that though I was part of a team that was able to deliver excellent treatment services to an extremely vulnerable population, I did not have a full understanding of the sociocultural context in which they lived. I admitted recently to a friend that I had a whole lot of patients whose lives I could not 'control'. But this journey has been about understanding that I do not have to 'control', I just have to understand. Hopefully this thesis will be just one of the steps to understanding PLHIV and making their lives, and those of their children, easier. Recognition of the multi-level and multi-factor influences on the desire to have children will help my fellow health workers and managers at local, national and international levels in the design of culturally appropriate, multi-level programs that meet the needs of people living with HIV and their children. This study clearly elucidates areas where interventions can be deployed in order to achieve this important outcome.

"We health workers have to step back and see our patients for who they are. They are not diseases, they are people"

Barbara Nattabi
September 2011

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APPENDICES

APPENDICES

APPENDIX 1: Phases of the study

Phases of the study:

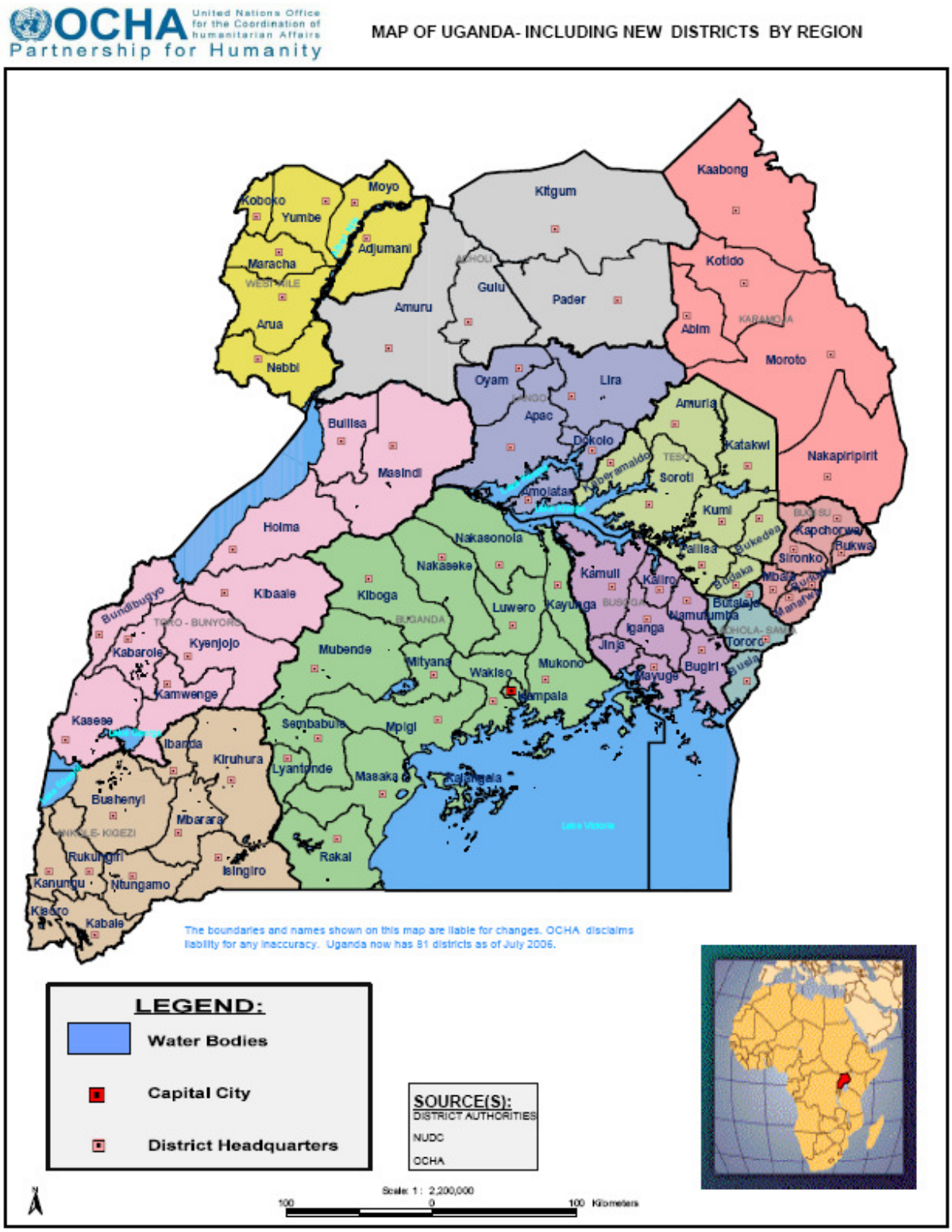
Phase		Respondents	Purpose	Methods	Tool
Phase 1		Key stakeholder from Ministry of Health HIV and Reproductive Health divisions, UNICEF, UNFPA	Identified the availability and the delivery of family planning services to HIV infected women and men in Northern Uganda	Semi structured interviews	Semi structured schedule
Phase 2	Part 1	Administrators from three health facilities in Gulu district	Identified family planning services provided and the level of integration of family planning services with HIV/AIDS care and prevention services at the health facility level		Health facility tool
	Part 2	476 respondents	Quantitative study	Structured interviews	Structured questionnaire
	Part 3	26 participants	Qualitative study	In-depth interviews	Semi structured question guide

APPENDIX 2: Matrix of objectives and associated methodology summary

Objectives	Methods	Instrument	Analysis
(i(a) To describe the determinants of fertility desires and intentions of the HIV infected women and men attending three HIV clinics in Gulu district	(i) One to one interviews with 476 respondents	Structured questionnaire	Quantitative data analyzed using SPSS
(i(b) To explore the determinants of fertility desires and intentions of the HIV infected women and men attending in Gulu district	(ii) One to one in-depth interviews with 26 participants (13 men and 13 women)	(i) Audiotape recordings and transcriptions (ii) Semi-structured interview schedule for in-depth interviews	NVivo software used to assist with management and analysis of Qualitative data
(ii(a) To investigate access to family planning services among HIV infected women and men attending three HIV clinics in Gulu district	(i) One to one interviews with 476 respondents	Structured questionnaire	Quantitative data analyzed using SPSS
(ii (b) to explore the structural/environmental, community and individual factors that enhance or restrict their ability to plan, space and limit their family sizes.	(ii) One to one in-depth interviews with 26 participants (13 men and 13 women)	(i) Audiotape recordings and transcriptions (ii) Semi-structured interview schedule for In-depth interviews	NVivo software used to assist with management and analysis of Qualitative data

(iii) To investigate the level of integration of family planning services with HIV/AIDS Programs at Health facility and National program levels	(i) One to one interviews with Health Facility administrators at the three HIV clinics	Health facility tool	
	(ii) A survey of key stakeholders in Gulu district and Ministry of Health Officials in Kampala	Stakeholder interview	
(iv) To suggest an appropriate model for delivery of family planning services to the HIV infected women and men attending these HIV clinics in Gulu district, with possible implications for HIV positive populations in other regions in Uganda	(i) One to one interviews with 476 respondents	Structured questionnaire	Quantitative data analyzed using SPSS

APPENDIX 3: Map of Uganda showing Gulu district, Northern Uganda



APPENDIX 4: Stratified sampling by age and gender

	Lacor		Gulu Regional		TASO		
Age group (years)	female	male	female	male	female	male	Total
15-19	12	12	7	7	15	15	68
20-24	12	12	7	7	15	15	68
25-29	12	12	7	7	15	15	68
30-34	12	12	7	7	15	15	68
35-39	12	12	7	7	15	15	68
40-44	12	12	7	7	15	15	68
45-49	12	12	7	7	15	15	68
Total	84	84	49	49	105	105	476

APPENDIX 5: Women's questionnaire (English)

WOMEN'S QUESTIONNAIRE (ENGLISH) **Questionnaire ID _____**

Date of interview_____ **Name of interviewer_____**

Language of interview_____

Instructions to Interviewer: CIRCLE THE CODE NUMBER NEXT TO THE ANSWER GIVEN

SECTION 1. RESPONDENT'S BACKGROUND

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q1	GENDER OF RESPONDENT	Male 1 Female 2	
Q2	Where do you live? Village:_____ Parish:_____ Sub county:_____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q3	How long have you been living in (NAME OF CURRENT PLACE OF RESIDENCE)?	Years ☐☐ Always 95 →	GO TO Q5
		Visitor 96	
Q4	Just before you moved here, where did you live? Place: _____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q5	What day, month and year were you born?	Day ☐☐ Month ☐☐ Year ☐☐☐☐	
Q6	How old were you at your last birthday?	Years old ☐☐ (Age completed in years) CROSS-CHECK WITH DATE OF BIRTH AND RECONCILE	
Q7	Have you ever attended school?	Yes 1 No 2 →	GO TO Q10

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q8	What is the highest level of school you attended: primary, '0' level, 'A' level, or university or tertiary? (CIRCLE HIGHEST SCHOOL LEVEL)	Primary 1 'O" level 2 'A' level 3 Tertiary 4 University 5	
Q9	What is the highest class/year you completed at that level?	Class/Year ☐☐	
Q10	What is your religion?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6 Other……(SPECIFY) 7	
Q11	What is your occupation? _____	Not employed 1 Business 2 Police/military 3 Student 4 Farmer 5 Housewife 6 Professional 7 Other…… 8	
Q12	What is your marital status now: are you single, married, cohabiting, widowed, divorced or separated/	Single/never married 1 Married 2 Cohabiting 3 Widowed 4 Divorced 5 Separated 6 Other…… 7	→ GO TO SECTION 2

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q13	Does/Did your husband/partner have other wives or does he live with other women as if married? (ASK IF MARRIED, COHABITING, DIVORCED OR SEPARATED)	Yes 1 No 2 Don't know 3	GO TO Q15
Q14	Are you the first, second, … wife?	Rank ☐☐	
Q15	How old was your husband/partner on his last birthday?	Years old ☐☐ (Age completed in years)	
Q16	Did your husband ever attend school?	Yes 1 No 2 Don't know 3	GO TO Q19
Q17	What was the highest level of school he attended: primary, '0' level, 'A' level, or university or tertiary?	Primary 1 'O" level 2 'A' level 3 Tertiary 4 University 5 Don't know 6	GO TO Q19
Q18	What is the highest class/year he completed at that level?	Class/Year ☐☐ Don't Know 9	
Q19	What is his religion?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6 Other (Specify) 7	
Q20	What is his occupation? _____	Not employed 1 Business 2 Police/military 3 Student 4	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Farmer 5 Housewife 6 Professional 7 Other…… 8	

SECTION 2. REPRODUCTION

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q21	Now I would like to ask about all the births you have had during your life. Have you ever given birth?	Yes 1 No 2 →	GO TO Q24
Q22	How many births have you had in total?	☐☐	

Q23	Now I would like to record all the births, whether alive or not, starting with the first one you had				
Child number	Sex of child	Is child still alive?	Age (in years)	If dead, how old was the child when died?	Cause of death if known
1st born	Boy 1 Girl 2	Yes 1 No 2 →			
2nd born	Boy 1 Girl 2	Yes 1 No 2 →			
3rd born	Boy 1 Girl 2	Yes 1 No 2 →			
4th born	Boy 1 Girl 2	Yes 1 No 2 →			
5th born	Boy 1 Girl 2	Yes 1 No 2 →			
6th born	Boy 1 Girl 2	Yes 1 No 2 →			
IF MORE THAN 6 CHILDREN USE AN EXTRA SHEET					

Q24	Are you pregnant now?	Yes 1 No 2 →	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Don't know 3	→ GO TO Q27
Q25	How many months pregnant are you?	Months ☐☐	
Q26	At the time you became pregnant, did you want to become pregnant then, did you want to wait until later, or did you not want to have any (more) children at all?	Wanted to become pregnant 1 Wanted to wait till later 2 Did not want any more children 3	
Q27	Have you ever had a pregnancy that was miscarried, was aborted, or ended in a stillbirth?	Yes 1 No 2 Don't know 3	

SECTION 3. CONTRACEPTION

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q28	Now I would like to talk about family planning - the various ways or methods that a couple can use to delay or avoid a pregnancy. Which ways or methods have you heard about? FOR METHODS NOT MENTIONED SPONTANEOUSLY, ASK: Have you ever heard of (METHOD)? CIRCLE CODE 1 FOR EACH METHOD MENTIONED SPONTANEOUSLY. THEN PROCEED DOWN COLUMN, READING THE NAME AND DESCRIPTION OF EACH METHOD NOT MENTIONED SPONTANEOUSLY. CIRCLE CODE 1 IF METHOD IS RECOGNIZED, AND CODE 2 IF NOT RECOGNIZED. THEN, FOR EACH METHOD WITH CODE 1 CIRCLED IN A, ASK B.	**A**	**B**: Have you or your husband ever used this method?
			Have you ever had an operation to avoid having any more children?
Q29	FEMALE STERILIZATION Women can have an operation to avoid having any more children.	Yes 1 No 2	Yes 1 No 2
Q30	MALE STERILIZATION Men can have an operation to avoid having any more children.	Yes 1 No 2	Have you ever had a partner who had an operation to avoid having any more children? Yes 1 No 2
Q31	PILL Women can take a pill every day to avoid becoming pregnant	Yes 1 No 2	Yes 1 No 2
Q32	IUD Women can have a loop or coil placed inside them by a doctor or a nurse	Yes 1	Yes 1

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		No 2	No 2
Q33	INJECTABLES Women can have an injection by a health provider that stops them from becoming pregnant for one or more months.	Yes 1 No 2	Yes 1 No 2
Q34	IMPLANTS Women can have several small rods placed in their upper arm by a doctor or nurse which can prevent pregnancy for one or more years	Yes 1 No 2	Yes 1 No 2
Q35	CONDOM Men can put a rubber sheath on their penis before sexual intercourse	Yes 1 No 2	Yes 1 No 2
Q36	FEMALE CONDOM Women can place a sheath in their vagina before sexual intercourse	Yes 1 No 2	Yes 1 No 2
Q37	LACTATIONAL AMENORRHEA METHOD (LAM). After a mother has given birth, she breastfeeds exclusively so that she does not get pregnant for at least the first 6 months	Yes 1 No 2	Yes 1 No 2
Q38	RHYTHM METHOD Every month that a woman is sexually active she can avoid pregnancy by not having sexual intercourse on the days of the month she is most likely to get pregnant.	Yes 1 No 2	Yes 1 No 2
Q39	WITHDRAWAL Men can be careful and pull out before climax.	Yes 1 No 2	Yes 1 No 2
Q40	EMERGENCY CONTRACEPTION As an emergency measure after unprotected sexual intercourse, women can take special pills at any time within five days to prevent pregnancy.	Yes 1 No 2	Yes 1 No 2
Q41	Have you heard of any other ways or methods that women or men can use to avoid pregnancy?	Yes 1 Specify _____ No 2	Yes 1 No 2

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q42	Are you currently doing something or using any method to delay or avoid getting pregnant?	Yes 1 No 2 →	GO TO Q47
Q43	Does your husband/partner know that you are using a method of family planning?	Yes 1 No 2	
Q44	Which method are you using? (IF MORE THAN ONE METHOD, CIRCLE ALL MENTIONED)	FEMALE STERILIZATION 1 MALE STERILIZATION 2 PILL 3	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		IUD 4 INJECTABLES 5 IMPLANTS 6 CONDOM 7 FEMALE CONDOM 8 DIAPHRAGM 9 FOAM/JELLY 10 LACTATIONAL AMEN 11 RHYTHM METHOD 12 WITHDRAWAL 13 Other……(SPECIFY) 14	
Q45	Where do you obtain (CURRENT METHOD) the last time? IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE _____ (NAME OF PLACE)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED DISTRIBUTOR 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 NGO COMMUNITY BASED DISTRIBUTOR 11 OTHER PRIVATE MEDICAL_____ 12 **OTHER SOURCE** SHOP 13 RELIGIOUS INSTITUTION 14 FRIEND/RELATIVE 15 Other 16	
Q46	Where would you prefer to obtain your method? _____ (NAME OF PLACE	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED DISTRIBUTOR 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 NGO COMMUNITY BASED DISTRIBUTOR 11 OTHER PRIVATE MEDICAL_____ 12 **OTHER SOURCE** SHOP 13 RELIGIOUS INSTITUTION 14 FRIEND/RELATIVE 15	

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
		Other	16	
Q47	Do you think you will use a contraceptive method to delay or avoid pregnancy at any time in the future?	Yes	1	
		No	2	
		Don't know	3	GO TO Q49
Q48	Which contraceptive method would you prefer to use?	FEMALE STERILIZATION	1	GO TO Q50
		MALE STERILIZATION	2	
		PILL	3	
		IUD	4	
		INJECTABLES	5	
		IMPLANTS	6	
		CONDOM	7	
		FEMALE CONDOM	8	
		DIAPHRAGM	9	
		FOAM/JELLY	10	
		LACTATIONAL AMEN	11	
		RHYTHM METHOD	12	
		WITHDRAWAL	13	
		Other……(SPECIFY)	14	
Q49	What is the main reason that you think you will not use a contraceptive method at any time in the future?	Not married	1	
		Fertility related reasons		
		Not having sex	2	
		Infrequent sex	3	
		My wife is menopausal/ or had a hysterectomy	4	
		Subfecund/infecund	5	
		Postpartum amenorrheic	6	
		Breastfeeding	7	
		Fatalistic	8	
		Opposition to use		
		Respondent opposed	9	
		Wife opposed	10	
		Others opposed	11	
		Religious prohibition	12	
		Lack of knowledge		
		Knows no methods	13	
		Knows no source	14	
		Method-related reasons		
		Health concerns	15	
		Fear of side effects	16	
		Lack of access/too far	17	
		Costs too much	18	
		Inconvenient to use	19	
		Interferes with body's normal processes	20	
		Other……	21	
		Don't know	98	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q50	Did any health worker member at the health facility speak to you about family planning methods?	Yes 1 No 2	
Q51	Would you say that using contraception is mainly your decision, mainly your husband's/partner's decision, or did you both decide together?	Mainly respondent 1 Mainly husband/partner 2 Joint decision 3 Other(Specify) 6	
Q52	Do you think that taking contraception is a woman's responsibility, man's responsibility or both?	Woman's 1 Man's 2 Both woman's and man's responsibility 3 Other (Specify) 6	
Q53	How often have you talked to your husband/partner about Family Planning in the past year?	Never 1 Once or twice 2 More often 3	
Q54	In the last six months have you seen or heard about family planning: a) On the radio? b) On the television? c) In a newspaper or magazine? d) On a sign or pamphlet? e) In a video or film?		

	Yes	No
Radio	1	2
Television	1	2
Newspaper/magazine	1	2
Sign or pamphlet	1	2
Video/film	1	2

SECTION 4. FERTILITY PREFERENCES

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
ASK **A** OR **B** DEPENDING ON WHETHER SHE IS PREGNANT OR NOT				
A. NOT PREGNANT OR UNSURE:				
Q55	Now I have some questions about the future. Would you like to have a/another child or would you prefer not to have any (more) children?	Have a/another child	1	G0 TO Q56
		No more/none	2	GO TO Q57
		Says she can't get pregnant	3	GO TO Q63
		Undecided/don't know	4	GO TO Q58

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q56	IF RESPONDENT ANSWERS 1, ASK: **Why do you want** more children WRITE EXACTLY WHAT THE RESPONDENT SAYS →		
Q57	IF RESPONDENT ANSWERS 2, ASK **Why don't** you want more children? WRITE EXACTLY WHAT THE RESPONDENT SAYS →		
Q58	How long would you like to wait from now before the birth of a/another child?	Months 1 Years 2 Soon/now 3 Says she can't get pregnant 4 After marriage 5 Other (Specify) _____ 6 Don't know 7	GO TO Q63
B. PREGNANT			
Q59	Now I have some questions about the future. After the child you are expecting now, would you like to have another child, or would you prefer not to have any more children?	Have a/another child 1 No more/none 2 Undecided/don't know 3	TO Q60 TO Q61 TO Q65
Q60	IF THE RESPONDENT ANSWERS 1, ASK: **Why do you want** more children WRITE EXACTLY WHAT THE RESPONDENT SAYS →		
Q61	IF THE RESPONDENT ANSWERS 2, ASK: **Why don't** you want more children? WRITE EXACTLY WHAT THE RESPONDENT SAYS →		
Q62	After the birth of the child you are expecting now, how long would you like to wait before the birth of another child?	Months 1 Years 2 Soon/now 3 After marriage 4 Other (Specify) _____ 5	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Don't know 6	
Q63	How many more children do you want to have?		
Q64	How many more children do you intend to have?		
Q65	Does your husband/partner want any more children?	Yes 1 No 2 Don't know 3	GO TO Q69
Q66	How many more children does he want to have?		
Q67	How important is it to your husband to have more children?	Very Important 1 Important 2 Somewhat important 3 Not important 4 Don't know 5	
Q68	Does your husband/partner want the same number of children that you want, or does he want more or fewer than you want?	Same number 1 More children 2 Fewer children 3 Don't know 4	
Q69	**THIS QUESTION SHOULD BE ASKED OF THOSE WHO DO NOT WANT A CHILD SOON OR DO NOT WANT ANY MORE CHILDREN BUT ARE NOT USING ANY FORM OF CONTRCEPTION I.E. THEY SAID NO TO QUESTIONS 39, 51 AND 55. ASK EITHER A OR B** **A. WANTS TO HAVE A/ANOTHER CHILD**: You have said that you do not want a/another child soon, but you are not using any method to avoid pregnancy. **OR** **B. WANTS NO MORE /NONE**: You have said that you do not want any (more) children, but you are not using any method to avoid pregnancy.		
	Can you tell me why you are not using a method? Any other reason? RECORD ALL REASONS MENTIONED.	Not married 1 **Fertility related reasons** Not having sex 2 Infrequent sex 3 Menopausal/ hysterectomy 4 Subfecund/infecund 5 Postpartum amenorrheic 6 Breastfeeding 7 Fatalistic 8 **Opposition to use** Respondent opposed 9 Husband/partner opposed 10 Others opposed 11 Religious prohibition 12	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Lack of knowledge Knows no methods 13 Knows no source 14 **Method-related reasons** Health concerns 15 Fear of side effects 16 Lack of access/too far 17 Costs too much 18 Inconvenient to use 19 Interferes with body's normal processes 20 Other…… 21 Don't know 98	
Q70	**ASK EITHER A OR B** **A. HAS LIVING CHILDREN:** if you could go back to the time you did not have any children and could choose exactly the number of children to have in your whole life, how many would that be? **OR** **B. NO LIVING CHILDREN**: if you could choose exactly the number of children to have in your whole life, how many would that be?	None 1 Number Other (specify) _____ 3	GO TO SECTION 5 G0 TO Q71

No.	QUESTIONS AND FILTERS					SKIP
Q71	How many of these children would you like to be boys, how many would you like to be girls and for how many would the sex not matter?	Boys	Girls	Either		
		Other (specify) _____				

SECTION 5. HIV KNOWLEDGE

No.	QUESTIONS AND FILTERS	CODING CATEGORY			SKIP
	Now I would like to ask to ask you some questions about AIDS				
Q72	Can the virus that causes AIDS be transmitted from a mother to her baby: a) During pregnancy? b) During delivery? c) By breastfeeding?		Yes	No	Don't know
		During pregnancy	1	2	3
		During delivery	1	2	3
		Breastfeeding	1	2	3
Q73	Are there any special drugs that a doctor or a nurse can give to a woman infected with the AIDS virus to reduce the risk of transmission to the baby?	Yes 1 No 2 Don't know 3			GO TO Q76

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q74	Do you know of a place where a pregnant woman with the AIDS virus can go to get this drug to reduce the risk of her baby getting the AIDS virus?	Yes 1 No 2 →	GO TO Q76
Q75	Where is this place? PROBE: Any other place? PROBE TO IDENTIFY THE TYPE OF SOURCE AND CIRCLE THE APPROPRIATE CODES. IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE. _____ (NAME OF PLACE/S)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14	
Q76	Have you heard about any drugs that people infected with the AIDS virus can get from a doctor or a nurse to help them live longer?	Yes 1 No 2 Don't know 3 →	TO SECTION 6
Q77	In the past six months, have you seen or heard anything about drug treatments for AIDS: a) On the radio? b) On the television? c) In a newspaper or magazine? d) On a sign or pamphlet? e) In a video or film?	Yes / No Radio 1 2 Television 1 2 Newspaper or magazine 1 2 Sign or pamphlet 1 2 Video/film	
Q78	What drugs do you know about? PROBE: Any other drugs?	Antiretroviral drugs 1 Septrin 2 Other drugs (Specify)_____ 3 Don't know 4	
Q79	Do you know of a place to get Antiretroviral drugs?	Yes 1 No 2 →	TO Q81
Q80	Where is this place? PROBE: Any other place? PROBE TO IDENTIFY THE TYPE OF SOURCE	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	AND CIRCLE THE APPROPRIATE CODE. IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE. _____ (NAME OF PLACE/S)	FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14	
Q81	Now I'd like to ask you some questions about the Antiretroviral treatment (ART) that is available to people with AIDS virus. For each statement I read, please tell me if you agree or disagree with it a) ART is not a cure for the AIDS virus. b) A person receiving ART cannot transmit the virus to others c) Once ART is started, a patient must continue treatment for the rest of his/her life. d) People who know they are HIV positive should wait until they feel sick to see a doctor or nurse about ART. e) Failing to follow ART as directed can make the AIDS virus become stronger and even harder to control.	Cure: Agree 1, Disagree 2, Don't 8 Transmit: Agree 1, Disagree 2, Don't 8 Continue ART: Agree 1, Disagree 2, Don't 8 Wait until sick: Agree 1, Disagree 2, Don't 8 As directed: Agree 1, Disagree 2, Don't 8	

SECTION 6. HIV HISTORY

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q82	When was your HIV diagnosis made?	Month ☐☐ Year ☐☐☐☐	
Q83	How long have you been attending this clinic?	Months ☐☐ Years ☐☐	
Q84	Were you pregnant at the time when your diagnosis was made?	Yes 1 No 2	
Q85	Are you presently taking Anti-retroviral therapy?	Yes 1 No 2 →	GO TO Q89
Q86	Which combination of Antiretroviral drugs are you taking?		

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q87	For how long have you been taking Antiretroviral therapy?	Months ☐☐ Years ☐☐	
Q88	Since you began to take Antiretroviral therapy, do you feel healthier?	Yes 1 No 2	
Q89	Are you currently taking Septrin?	Yes 1 No 2	
Q90	Have you disclosed your HIV status to your husband?	Yes 1 No 2 Not applicable 3	
Q91	Have you disclosed you HIV status to your:	Yes / No Mother 1 / 2 Mother-in-law 1 / 2 Children 1 / 2	
Q92	What is the HIV status of your husband?	Positive 1 Negative 2 Not applicable 3 Don't Know 4	
Q93	Is your husband taking Anti-retroviral therapy?	Yes 1 No 2 Not applicable 3 Don't Know 4	
Q94	Are any of your children HIV positive?	Yes 1 No 2 Not applicable 3 Don't Know 4	

SECTION 7. HIV/AIDS and Stigma

I'm going to read a list of events that may have happened to you during the past three months. After I read each item, please tell me how often it happened to you because of your HIV status:				
In the past 3 months, how often did the following events happen because of your HIV status?	Never	Once or twice	Several times	Most of the time

Q95. I was told to use my own eating utensils.	□	□	□	□
Q96. I was asked not to touch someone's child.	□	□	□	□
Q97. I was made to drink last from the cup.	□	□	□	□
Q98. Someone mocked me when I passed by.	□	□	□	□
Q99. I stopped eating with other people.	□	□	□	□
Q100. I was asked to leave because I was coughing.	□	□	□	□
Q101. Someone stopped being my friend.	□	□	□	□
Q102. A friend would not chat with me.	□	□	□	□
Q103. I was called bad names.	□	□	□	□
Q104. People sang offensive songs when I passed by.	□	□	□	□
Q105. I was told that I have no future.	□	□	□	□
Q106. Someone scolded me.	□	□	□	□
Q107. I was told that God is punishing me.	□	□	□	□
Q108. I was made to eat alone.	□	□	□	□
Q109. Someone insulted me.	□	□	□	□
Q110. People avoided me	□	□	□	□
Q111. People cut down visiting me	□	□	□	□
Q112. People ended their relationships with me	□	□	□	□
In the past 3 months, how often did the following events happen <u>because of your HIV status</u>?	Never	Once or twice	Several times	Most of the time
Q113. I was blamed for my HIV status	□	□	□	□
Q114. Someone tried to get me fired from my job.	□	□	□	□
Q115. My employer denied me opportunities.	□	□	□	□
The next set of questions is about your experiences <u>in the hospital or clinic</u>.				

In the past 3 months, how often did the following events happen because of your HIV status?	Never	Once or twice	Several times	Most of the time
Q116. I was denied health care.	□	□	□	□
Q117. I was refused treatment because I was told I was going to die anyway.	□	□	□	□
Q118. I was discharged from the hospital while still needing care.	□	□	□	□
Q119. I was shuttled around instead of being helped by a nurse.	□	□	□	□
Q120. At the hospital/clinic, I was made to wait until last	□	□	□	□
Q121. At the hospital, I was left in a soiled bed.	□	□	□	□
Q122. In the hospital or /clinic, my pain was ignored.	□	□	□	□
These questions are about some of your thoughts or feelings.				
Q123. How often have you thought or felt this way during the past 3 months because of your HIV status?	Never	Once or twice	Several times	Most of the time
Q124. I felt that I did not deserve to live.	□	□	□	□
Q125. I felt ashamed of having this disease.	□	□	□	□
Q126. I felt completely worthless.	□	□	□	□
Q127. I felt that I brought a lot of trouble to my family.	□	□	□	□
Q128. I felt that I am no longer a person.	□	□	□	□

THANK YOU FOR PARTICIPATING IN THIS INTERVIEW.

APPENDIX 6: Women's questionaire (Luo)

WOMEN'S QUESTIONNAIRE (LUO)

LAPENY PA MON **Questionnaire ID _____**

Nino me interview_____ **Nying lapeny_____**

Lep ma ki tiyo kede i peny man_____

Instructions to Interviewer: CIRCLE THE CODE NUMBER NEXT TO THE ANSWER GIVEN

SECTION 1. RESPONDENT'S BACKGROUND

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q1	COO NYO MON	Male 1 Female 2	
Q2	I Bedo Kwene? Caaro :_____ Parish:_____ Sub county:_____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q3	Iri Kany pi kare marom mene	Years ☐☐ Always 95 Visitor 96	→ GO TO Q5
Q4	Nongo lbedo kwene mapud pe kobo kanya Kabedo: _____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q5	Nino mene, Dye mene kede mwaka mene ma kinwalo iye ?	Day ☐☐ Month ☐☐ Year ☐☐☐☐	
Q6	Mwaki ni adi ?	Years old ☐☐ (Age completed in years) CROSS-CHECK WITH DATE OF BIRTH AND RECONCILE	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q7	Onongov Itemo kwan?	Yes 1 No 2 →	GO TO Q10
Q8	Rwom kwani ogik kwene? (CIRCLE HIGHEST SCHOOL LEVEL)	Primary 1 'O" level 2 'A' level 3 Tertiary 4 University 5	
Q9	I gik i kilaaci adi?	Class/Year ☐☐	
Q10	Dini ni aye mene?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6 Other……(SPECIFY) 7	
Q11	Itiyo tic ango? _____	Not employed 1 Business 2 Police/military 3 Student 4 Farmer 5 Housewife 6 Professional 7 Other…… 8	
Q12	Inyome?	Single/never married 1 → Married 2 Cohabiting 3 Widowed 4 Divorced 5 Separated 6	GO TO SECTION 2

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Other…… 7	
Q13	Cwari tye ki dako onyo mon mukene ma bedo kwedgi? (ASK IF MARRIED, COHABITING, DIVORCED OR SEPARATED)	Yes 1 No 2 Don't know 3	GO TO Q15
Q14	Inye dako me Acel, Ariyo,…?	Rank ☐☐	
Q15	Cwari tye ki mwaka addi?	Years old ☐☐ (Age completed in years)	
Q16	Cwari okwano?	Yes 1 No 2 Don't know 3	GO TO Q19
Q17	Rwom kwan ne ogik kwene?	Primary 1 'O" level 2 'A' level 3 Tertiary 4 University 5 Don't know 6	GO TO Q19
Q18	Cwari ogik i kilaaci adi?	Don't Know ☐☐	
Q19	Cwari lubo dini mene?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6 Other (Specify) _____ 7	
Q20		Not employed 1	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	Cwari tiyo tic ango? _____	Business 2 Police/military 3 Student 4 Farmer 5 Housewife 6 Professional 7 Other…… 8	

SECTION 2. REPRODUCTION

No.	QUESTIONS AND FILTERS		CODING CATEGORY			SKIP
Q21	Kumbedi amito penyo lok ikom lutino mo kiken ma inwyalo ikwoni. Ya inwyal?		Yes 1 No 2 →			GO TO Q24
Q22	Inwyal kidi?		☐☐			
Q23	Dong amito cooyo lok kum lutino ma inywalo, ma kwo ki mutoo, caakoki latin me acel					
Latin me adi?	Latin awobi onyo nyako		Latin kwo?		Mwaka pa latin	Ka oto,nyo tye ki mwaka adi?	Ngo ma Oneko?
Me Acel	Awobi 1 Anyaka 2		Yes 1 No 2 →				
Me ariyo	1 Awobi Anyaka 2		Yes 1 No 2 →				
Me adek	Awobi 1 Anyaka 2		Yes 1 No 2 →				
Me angwen	Awobi 1 Anyaka 2		Yes 1 No 2 →				
Me abic	Awobi 1 Anyaka 2		Yes 1 No 2 →				
Me abicel	Awobi 1 Anyaka 2		Yes 1 No 2 →				
IF MORE THAN 6 CHILDREN USE AN EXTRA SHEET							
Q24	Kombedi yii tye/ I yac?		Yes 1				

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		No 2 Don't know 3	→ GO TO Q27
Q25	Dwe adi?	Months ☐☐	
Q26	Kare ma iyac , nongo imito?, nongo imito yacu lacen , kede nongo dong igiku nywal?	Wanted to become pregnant 1 Wanted to wait till later 2 Did not want any more children 3	
Q27	Ya i onyo yi?,ya yi ony?, ya inywalu latin ma oto?	Yes 1 No 2 Don't know 3	

SECTION 3. CONTRACEPTION

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q28	Kombedi amito lok ikom Lago nywal – yoo mapat-pat ma jo munyome twero juko nyo galo ki yaco FOR METHODS NOT MENTIONED SPONTANEOUSLY, ASK: Have you ever heard of (METHOD)? CIRCLE CODE 1 FOR EACH METHOD MENTIONED SPONTANEOUSLY. THEN PROCEED DOWN COLUMN, READING THE NAME AND DESCRIPTION OF EACH METHOD NOT MENTIONED SPONTANEOUSLY. CIRCLE CODE 1 IF METHOD IS RECOGNIZED, AND CODE 2 IF NOT RECOGNIZED. THEN, FOR EACH METHOD WITH CODE 1 CIRCLED IN A, ASK B.	**A**	**B**: In nyo cwari otiyo ki yoo mene? Ki yangо in me juku nywal?
Q29	Dako romo nongo ayango manok ci tweyo ocike ma kelo tonge ci dong pe binongo latin matwal	Yes 1 No 2	Yes 1 No 2
Q30	Laco romo nongo ayango manok ci tweyo ocike ma kelo lac co ci pe romo nywalo latin mo keken	Yes 1 No 2	I bedo ki lawoti ma onongo yang me juku nywal? Yes 1 No 2
Q31	Dako twero mwonyo yat nino ducu ci pe yac	Yes 1	Yes 1

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		No 2	No 2
Q32	dako romo tic ki waya ma orine ma nyodo me juku yaco	Yes 1 No 2	Yes 1 No 2
Q33	Dako twero nongo libira ki bot lutic I ot yat me juko nyodo pi dwe acel onyo ma kato	Yes 1 No 2	Yes 1 No 2
Q34	Dako twero nongo yat makirwako Ibade ki bot daktar me juku nyodo pi dwe acel onyo ma kato	Yes 1 No 2	Yes 1 No 2
Q35	Coo twero ruko roc bol (Kondom) ikome me coo ma poya obutu ki dako	Yes 1 No 2	Yes 1 No 2
Q36	Dako twero kero roc bol (kondom) ikome me mon ma poya obutu ki laco	Yes 1 No 2	Yes 1 No 2
Q37	LACTATIONAL AMENORRHEA METHOD (LAM). Ki inge nyal, Doto Latin pi kare malac gengo gamo yic pi dwe abicel onyo ma caro	Yes 1 No 2	Yes 1 No 2
Q38	RHYTHM METHOD Dwe ki dwe dako ma rwate ki cware twero lago nyodo ka pe butu ki cware ikare ma en ngeyo ni eromo yac iye.	Yes 1 No 2	Yes 1 No 2
Q39	WITHDRAWAL Laco twero gwoke ka wote dako ma nongo peya olaya lac pa coo	Yes 1 No 2	Yes 1 No 2
Q40	EMERGENCY CONTRACEPTION Ki inge butu ki laco, dako romo munyo yat ma kiyubu me juku gamo yic inino abic.	Yes 1 No 2	Yes 1 No 2
Q41	Dong iwinyo pi yo mukene ma dako romo tic kwede me juku gamo yic?	Yes 1 Specify _____ No 2	Yes 1 No 2

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q42	Kombedi itye katimu gimoo onyo tic ki yoo mukene me galu nyo juku gamo yic?	Yes 1 No 2 →	GO TO Q47
Q43	Cwari ngeyo ni itye ka tic ki yo mo me Lago kin nywal?	Yes 1	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		No 2	
Q44	Yo mene ma i tye ka tic kede (IF MORE THAN ONE METHOD, CIRCLE ALL MENTIONED)	FEMALE STERILIZATION 1 MALE STERILIZATION 2 PILL 3 IUD 4 INJECTABLES 5 IMPLANTS 6 KONDOM 7 KONDOM PA MON 8 DIAPHRAGM 9 FOAM/JELLY 10 LACTATIONAL AMEN 11 RHYTHM METHOD 12 WITHDRAWAL 13 Other……(SPECIFY) 14	
Q45	Igamo ki ot yat mene? IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE _____ (Nying kabedo)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED DISTRIBUTOR 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 NGO COMMUNITY BASED DISTRIBUTOR 11 OTHER PRIVATE MEDICAL_____ 12 **OTHER SOURCE** SHOP 13 RELIGIOUS INSTITUTION 14 FRIEND/RELATIVE 15 Other 16	
Q46	Kwene ma no imito gamo ki ye? _____ (Nying kabedo)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED DISTRIBUTOR 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8	

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
		PRIVATEDOCTOR/NURSE/MIDWIFE	9	
		OUTREACH	10	
		NGO COMMUNITY BASED DISTRIBUTOR	11	
		OTHER PRIVATE MEDICAL_____	12	
		OTHER SOURCE		
		SHOP	13	
		RELIGIOUS INSTITUTION	14	
		FRIEND/RELATIVE	15	
		Other	16	
Q47	Itamo ni i bi tiyo ki yo mo me galo nyo gengo gamo yic?	Yes	1	
		No	2	
		Don't know	3	GO TO Q49
Q48	Yo mene ma imito tic kwede?	FEMALE STERILIZATION	1	GO TO Q50
		MALE STERILIZATION	2	
		PILL	3	
		IUD	4	
		INJECTABLES	5	
		IMPLANTS	6	
		CONDOM	7	
		FEMALE CONDOM	8	
		DIAPHRAGM	9	
		FOAM/JELLY	10	
		LACTATIONAL AMEN	11	
		RHYTHM METHOD	12	
		WITHDRAWAL	13	
		Other……(SPECIFY)	14	
Q49	Pingo pi mito tic ki yo mo kiken me galo onyo gengo gamo yic?	Not married	1	
		Fertility related reasons		
		Not having sex	2	
		Infrequent sex	3	
		My wife is menopausal/ or had a	4	
		Subfecund/infecund	5	
		Postpartum amenorrheic	6	
		Breastfeeding	7	
		Fatalistic	8	
		Opposition to use		
		Respondent opposed	9	
		Wife opposed	10	
		Others opposed	11	
		Religious prohibition	12	
		Lack of knowledge		
		Knows no methods	13	
		Knows no source	14	
		Method-related reasons		

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Health concerns 15 Fear of side effects 16 Lack of access/too far 17 Costs too much 18 Inconvenient to use 19 Interferes with body's normal processes 20 Other…… 21 Don't know 98	
Q50	Dactar oloko kedi ikom yo ma pat pat mi Lago nywal?	Yes 1 No 2	
Q51	Anga ma yero yo ma otiyo kede me galo nyo gengo gamo yic? yin, dako, kede won ariyo wen?	Mainly respondent 1 Mainly husband/partner 2 Joint decision 3 Other(Specify) 6	
Q52	Tic ki yo mo me galo onyo gengo gamo yic tye I twero pa anga? Dako, Laco, kede gin ariyo weng?	Woman's 1 Man's 2 Both woman's and man's responsibility 3 Other (Specify) 6	
Q53	Iloko ki Cwari kidi i mwaka mukaro ikom Lago kin nywal?	Never 1 Once or twice 2 More often 3	
Q54	Ikin dwe abicel mukaro iwinyo pi Lago kin nywal: a) ki iredio? b) ki T.V? c) ki gajeti onyo karatac akwana? d) i sign post onyo waraga? e) i video/cinema	Yes / No Radio 1 2 Television 1 2 Newspaper/magazine 1 2 Sign or pamphlet 1 2 Video/film 1 2	

SECTION 4. FERTILITY PREFERENCES

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
ASK **A** OR **B** DEPENDING ON WHETHER SHE IS PREGNANT OR NOT				
A. NOT PREGNANT OR UNSURE:				
Q55	Kombedi amito penyi peny me kwo ni ma anyim. Imito lutino mukene?	Have a/another child	1	G0 TO Q56
		No more/none	2	GO TO Q57
		Says she can't get pregnant	3	GO TO Q63
		Undecided/don't know	4	GO TO Q58
Q56	IF RESPONDENT ANSWERS 1, ASK: Pingo imito lutino mukene? WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q57	IF RESPONDENT ANSWERS 2, ASK **Pingo pi imito lutino?** WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q58	I bi kuru pi kara ma rom kwene me nongo latin mukene?	Months	1	GO TO Q63
		Years	2	
		Soon/now	3	
		Says she can't get pregnant	4	
		After marriage	5	
		Other (Specify) _____	6	
		Don't know	7	
B. PREGNANT				
Q59	Kombedi amito penyi peny me kwo ni ma anyim. Ki enge latin man ma tye i yic, imito latin mukene, kede dong ideg lutino mukene?	Have a/another child	1	TO Q60
		No more/none	2	TO Q61
		Undecided/don't know	3	TO Q65
Q60	IF THE RESPONDENT ANSWERS 1, ASK: **Pingo imito lutino mukene?** WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q61	IF THE RESPONDENT ANSWERS 2, ASK: **Pingo pi mito Lutino mukene?** WRITE EXACTLY WHAT THE RESPONDENT SAYS →			

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q62	Ka inywal, i bi kuru pi kara ma rom kwene me nongo latin mukene?	Months 1 Years 2 Soon/now 3 After marriage 4 Other (Specify) _____ 5 Don't know 6	
Q63	Imito lutino adi?		
Q64	Imito medo lutino adi?		
Q65	Cwari mito lutino mukene?	Yes 1 No 2 Don't know 3	GO TO Q69
Q66	Cwari mito Lutino adi?		
Q67	Pire tek ki bot cwari ni omed lutino mukene?	Very Important 1 Important 2 Somewhat important 3 Not important 4 Don't know 5	
Q68	Cwari mito wel Lutino ma yin bene imito kede omito ma pat pat?	Same number 1 More children 2 Fewer children 3 Don't know 4	
Q69	**THIS QUESTION SHOULD BE ASKED OF THOSE WHO DO NOT WANT A CHILD SOON OR DO NOT WANT ANY MORE CHILDREN BUT ARE NOT USING ANY FORM OF CONTRCEPTION I.E. THEY SAID NO TO QUESTIONS 39, 51 AND 55. ASK EITHER A OR B** **A. WANTS TO HAVE A/ANOTHER CHILD**: I waki pi mito Latin mukene oyot yot ento pi tye ka tic ki yo mo me gengo gamo yic? **OR** **B. WANTS NO MORE /NONE**: I waki pi mito Lutino mukene ento pi tye ka tic ki yo mo me gengo gamo yic?		
	Pingo i pe ka tic ki yo mo me gengo nywal? RECORD ALL REASONS MENTIONED.	Not married 1 **Fertility related reasons** Not having sex 2 Infrequent sex 3	

No.	QUESTIONS AND FILTERS	CODING CATEGORY				SKIP
		Menopausal/ hysterectomy	4			
		Subfecund/infecund	5			
		Postpartum amenorrheic	6			
		Breastfeeding	7			
		Fatalistic	8			
		Opposition to use				
		Respondent opposed	9			
		Husband/partner opposed	10			
		Others opposed	11			
		Religious prohibition	12			
		Lack of knowledge				
		Knows no methods	13			
		Knows no source	14			
		Method-related reasons				
		Health concerns	15			
		Fear of side effects	16			
		Lack of access/too far	17			
		Costs too much	18			
		Inconvenient to use	19			
		Interferes with body's normal processes	20			
		Other……	21			
		Don't know	98			
Q70	**ASK EITHER A OR B** **A. HAS LIVING CHILDREN:** Ka nene iromo dok cen ikare ma peya onongo itye ki lotino mo keken, ka iromo cimo wel litino adi ma onongo ibimito? **OR** **B. NO LIVING CHILDREN**: **:** Ka iromo cimo wel litino ma imito ikwo ni kikome, onongo icimo adi?	None	1			GO TO SECTION 5
		Number				G0 TO Q71
		Other (specify) _____	3			
Q71	Onongo imiti Anyira kubed adi? Awobi adi? Adi ma onongo pe iparo ka nyaka nyo awobi?	Boys	Girls	Either		
		Other (specify) _____				

SECTION 5. HIV KNOWLEDGE

No.	QUESTIONS AND FILTERS	CODING CATEGORY				SKIP
	Kombedi amito penyo in ikom two Jonyo					
Q72	Kudi me two jonyo twero kobi Latin ki bot min ne? a) Ma Pud oyac? b) Ka nywal? c) Ka dot latin?		Yes	No	Don't know	
		During pregnancy	1	2	3	
		During delivery	1	2	3	

No.	QUESTIONS AND FILTERS	CODING CATEGORY				SKIP
		Breastfeeding	1	2	3	
Q73	Yat mo tye ma dactari miyo ki min latin mi temo gengo two man mi kobi Latin?	Yes 1 No 2 Don't know 3				GO TO Q76
Q74	I ngeyo kabedo mo ma mon mu yac gamo yat man ki ye?	Yes 1 No 2				GO TO Q76
Q75	Kwene? PROBE: Kabedo mukene tye? PROBE TO IDENTIFY THE TYPE OF SOURCE AND CIRCLE THE APPROPRIATE CODES. IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE. _____ (NAME OF PLACE/S)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14				
Q76	I winyo pi yat mo ma kimiyo ki Lutwo Cilim me medo kwogi?	Yes 1 No 2 Don't know 3				TO SECTION 6
Q77	I dwe abicel mukaro, iwinyo pi yadi nyo ineno yadi me konyo lutwo Jonyo? a) ki iredio? b) ki T.V? c) ki gajeti onyo karatac akwana? d) i sign post onyo waraga? e) i video/cinema		Yes	No		
		Radio	1	2		
		Television	1	2		
		Newspaper or magazine	1	2		
		Sign or pamphlet	1	2		
		Video/film	1	2		
Q78	Yadi mene ma ingeyo me konyo lutwo Jonyo? PROBE: Yat Mukene tye?	Antiretroviral drugs 1 Septrin 2 Other drugs (Specify)_____ 3				

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Don't know 4	
Q79	I ngeyo kabedo ma kigamo yadi man ki ye?	Yes 1 No 2 →	TO Q81
Q80	Yadi man kigamo ki kwene? PROBE: Kabedo mukene tye? PROBE TO IDENTIFY THE TYPE OF SOURCE AND CIRCLE THE APPROPRIATE CODE. IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE. _____ (NAME OF PLACE/S)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14	
Q81	Kombedi amito penyo in ikom yadi ma kitiyo kede me konyo jo ma tye ki two Jonyo. Amiti iwaca ka iyee kede pi yee lok ma bi titi. a) Yat ART pee cango two jonyo. b) Ngat ma munyo yat man pi kobo two bot ngat mukene. c) Ka ikyako tic kede, pi dong igiko ma twal. d) Jo ma gin ngeyo ni gin tye ki two jonyo myet gin okuu ka gin minyo kom gi lit yaka kun en dactar pi yat man. e) Munyo yat man I yoo mu poke ki ma dactari owacu medo two ameda dok bene weko yat pi tiyo mabe.	Agree / Disagree / Don't Cure 1 2 8 Transmit 1 2 8 Continue ART 1 2 8 Wait until sick 1 2 8 As directed 1 2 8	

SECTION 6. HIV HISTORY

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q82	I ngeyo pi two man(jonyo) awene?	Month ☐☐ Year ☐☐☐☐	
Q83	Dong ibino i ot yat kany pi kare marom kwene?	Months ☐☐ Years ☐☐	
Q84	Yii no tye?	Yes 1 No 2	
Q85	Itye ka munyo Yat me two jonyo(ARVs)?	Yes 1	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		No 2 →	GO TO Q89
Q86	Itye ka munyo Yadi mene?		
Q87	Dong imunyo yadi man pikare ma rom kwene?	Months ☐☐ Years ☐☐	
Q88	Aloka loka obedo tye ma icako tic ki Yadi mi two Jonyo?	Yes 1 No 2	
Q89	I munyo Septrin?	Yes 1 No 2	
Q90	Iniango cwari (won ot) ni itye ki two jonyo onyo I pe kwede?	Yes 1 No 2 Not applicable 3	
Q91	I waco ni itye ki two jonyo onyo pod pya I waco bot:	Yes awaco / No Pe awaco mamani 1 / 2 Min cwari 1 / 2 lotinoni 1 / 2	
Q92	Cwari (won ot) tyeki two jonyo onyo pe kwede	Positive 1 Negative 2 Not applicable 3 Don't Know 4	
Q93	Cwari tye ka mwonyo yat lajing two jonyo?	Yes 1 No 2 Not applicable 3 Don't Know 4	
Q94	Latin ma megi mo tye ki two jonyo?	Yes 1 No 2 Not applicable 3	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Don't Know 4	

SECTION 7. HIV/AIDS and Stigma

Abe kwano jami magi ma i kare mogo otimme i komi i dwe adek mukato ni. Ka akwano gi, wacca, tyen adi ma otimme i <u>komi pi lok kom two jonyo</u>				
I dwe Adek mukato ni, jami magi otimme I komi tyen adi?	pe otimme matwal	tyen acel onyo aryo	tyen madwong	kare ducu
Q95. Ki wacca ni atii ki jami cam ma mega	□	□	□	□
Q96. Ki wacca ni pe agud latin pa ngat mo	□	□	□	□
Q97. Ki weko an aye agiko mato pii kii i kikopo	□	□	□	□
Q98. Dano nyero an ka atye ka kato	□	□	□	□
Q99. A jukku cam ki dano	□	□	□	□
Q100. Ki ryema woko pien atye ka oono	□	□	□	□
Q101.Ngat mo ojukku bedo larema	□	□	□	□
Q102. Larema pe book lok ki an	□	□	□	□
Q103. Ki lwongo an ki nying ma raco	□	□	□	□
Q104. Dano owero wer marac ka atye ka kato	□	□	□	□
Q105. Ki wacca ni anyimma cok	□	□	□	□
Q106. Ngat mo odaa ki an	□	□	□	□
Q107.Ki wacca ni Rubanga tye ka pwodda	□	□	□	□
Q108. Ki weko acamo kena	□	□	□	□
Q109. Ngat mo oyeto an	□	□	□	□
Q110. Dano oweko an	□	□	□	□
Q111. Dano oweko limo an	□	□	□	□
Q112. Dano opokke ki an	□	□	□	□
I dwe Adek mukato ni, jami magi otimme I komi tyen adi?	pe otimme matwal	otimme tyen acel onyo aryo	otimme tyen mapol	otimme kare ducu

Q113. Ki wacco ni atimo bal pi nongo two jonyo	□	□	□	□
Q114. Ki temo ryemma ki i dog tic	□	□	□	□
Q115. Ladit tic okwero meddo rwom me ticca malo	□	□	□	□
Lapeny magi tye pi gin ma otimme i komi ki i ot yat				
I dwe Adek mukato ni, jami magi otimme I komi tyen adi?	pe otimme matwal	otimme tyen acel onyo aryo	otimme tyen mapol	otimme kare ducu
Q116. Pe ki miyo bot an kony	□	□	□	□
Q117. Pe ki miyo yat bot an pien ki wacca ni pud abe too woko	□	□	□	□
Q118. Ki kwanya ki i ot yat ma pud amito kony	□	□	□	□
Q119. Nurse obedo ka jungu an, labongo miyo kony	□	□	□	□
Q120.ki weko abedo ngat me agikki ki i ot yat	□	□	□	□
Q121. Ki weko a butu i wi kitanda ma col ki i ot yat	□	□	□	□
Q122. I ot yat, pe ki paro pi arem ma mega	□	□	□	□
Lapeny mago tye pi tam ni ki kit ma iwinyo kwede				
Q123. I winyo kuman tyen adi i dwe 3 ma okato ni pi lok me two jonyo ni?	pe awinyo matwal	kicel onyo kiryo	tyen mapol	I kare ducu
Q124. Atamo ni omyero atoo woko	□	□	□	□
Q125. Lewic omaka pi bedo ki two jonyo	□	□	□	□
Q126.Anongo ni konya peke	□	□	□	□
Q127. Anongo ni akelo peko mapol i gang wa	□	□	□	□
Q128. Anongo ni an dong pe adano.	□	□	□	□

APWOYO BEDO I LAPENY MAN

APPENDIX 7: Men's questionnaire (English)

MEN'S QUESTIONNAIRE (ENGLISH) **Questionnaire ID _____**

Date of interview_____ **Name of interviewer_____**

Language of interview_____

Instructions to Interviewer: CIRCLE THE CODE NUMBER NEXT TO THE ANSWER GIVEN

SECTION 1. RESPONDENT'S BACKGROUND

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q1	GENDER OF RESPONDENT	Male 1 Female 2	
Q2	Where do you live? Village:_____ Parish:_____ Sub county:_____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q3	How long have you been living in (NAME OF CURRENT PLACE OF RESIDENCE)?	Years ☐☐ Always 95 → GO TO Q5 Visitor 96	
Q4	Just before you moved here, where did you live? Place: _____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q5	What day, month and year were you born?	Day ☐☐ Month ☐☐ Year ☐☐☐☐	
Q6	How old were you at your last birthday?	Years old ☐☐ (Age completed in years) CROSS-CHECK WITH DATE OF BIRTH AND RECONCILE	
Q7	Have you ever attended school?	Yes 1 No 2 → GO TO Q10	
Q8	What is the highest level of school you attended: primary, '0' level, 'A' level, or	Primary 1 'O" level 2	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	university or tertiary? (CIRCLE HIGHEST SCHOOL LEVEL)	'A' level 3 Tertiary 4 University 5	
Q9	What is the highest class/year you completed at that level?	Class/Year ☐☐	
Q10	What is your religion?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6 Other……(SPECIFY) 7	
Q11	What is your occupation? _____	Not employed 1 Business 2 Police/military 3 Student 4 Farmer 5 Housewife 6 Professional 7 Other…… 8	
Q12	What is your marital status now: are you single, married, cohabiting, widowed, divorced or separated?	Single/never married 1 Married 2 Cohabiting 3 Widowed 4 Divorced 5 Separated 6 Other…… 7	→ GO TO SECTION 2
Q13	Do you have more than one wife or	Yes 1	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	woman you live with as if married?	No 2 →	GO TO Q15
Q14	Altogether, how many wives do you have or other partners you live with as if married?	☐☐	If more than one wife go to Q21
Q15	How old was your wife on her last birthday?	Years old ☐☐ (Age completed in years)	
Q16	Did your wife ever attend school?	Yes 1 No 2 → Don't know 3 →	GO TO Q19
Q17	What was the highest level of school she attended: primary, '0' level, 'A' level, or university or tertiary?	Primary 1 'O" level 2 'A' level 3 Tertiary 4 University 5 Don't know 6 →	GO TO Q19
Q18	What is the highest class/year she completed at that level?	Class/Year ☐☐ Don't Know 9	
Q19	What is her religion?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6 Other (Specify) 7	
Q20	What is her occupation? _____	Not employed 1 Business 2 Police/military 3 Student 4 Farmer 5 Housewife 6	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Professional 7 Other…… 8	

Q21. IF MORE THAN ONE WIFE (use the same codes as above):

Wife number	Age at last birthday	Attended School?	Highest level attended?	Religion	Occupation	Number of children by this wife	Presently pregnant?	Months pregnant?
1								
2								
3								
4								
5								
6								
7								
8								

SECTION 2. REPRODUCTION

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q22	Now I would like to ask about any children you have had during your life. I am interested in all the children that are biologically yours. Have you ever fathered any children with any woman?	Yes 1 No 2 Don't know 3 →	 GO TO SECTION 3
Q23	How many children have you had in total?	☐☐	
Q24	Now I would like to record all the children you have fathered, whether alive or not, starting with the first one you had		

Child number	Sex of child	Is child still alive?	Age (in years)	If dead, how old was the child when died?	Cause of death if known
1st born	Boy 1 Girl 2	Yes 1 No 2 →			
2nd born	Boy 1 Girl 2	Yes 1 No 2 →			

3rd born	Boy	1	Yes	1			
	Girl	2	No	2			
4th born	Boy	1	Yes	1			
	Girl	2	No	2			
5th born	Boy	1	Yes	1			
	Girl	2	No	2			
6th born	Boy	1	Yes	1			
	Girl	2	No	2			
IF MORE THAN 6 CHILDREN USE AN EXTRA SHEET							

SECTION 3. CONTRACEPTION

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q25	Now I would like to talk about family planning - the various ways or methods that a couple can use to delay or avoid a pregnancy. Which ways or methods have you heard about? FOR METHODS NOT MENTIONED SPONTANEOUSLY, ASK: Have you ever heard of (METHOD)? CIRCLE CODE 1 FOR EACH METHOD MENTIONED SPONTANEOUSLY. THEN PROCEED DOWN COLUMN, READING THE NAME AND DESCRIPTION OF EACH METHOD NOT MENTIONED SPONTANEOUSLY. CIRCLE CODE 1 IF METHOD IS RECOGNIZED, AND CODE 2 IF NOT RECOGNIZED. THEN, FOR EACH METHOD WITH CODE 1 CIRCLED IN A, ASK B.	**A**	**B**: Have you or your wife ever used this method?
Q26	FEMALE STERILIZATION Women can have an operation to avoid having any more children.	Yes 1 No 2	Yes 1 No 2
Q27	MALE STERILIZATION Men can have an operation to avoid having any more children.	Yes 1 No 2	Have you ever had an operation to avoid having any more children? Yes 1 No 2
Q28	PILL Women can take a pill every day to avoid becoming pregnant	Yes 1 No 2	Yes 1 No 2
Q29	IUD Women can have a loop or coil placed inside them by a doctor or a nurse	Yes 1 No 2	Yes 1 No 2
Q30	INJECTABLES Women can have an injection by a health provider that stops them from becoming pregnant for one or more	Yes 1	Yes 1

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	months.	No 2	No 2
Q31	IMPLANTS Women can have several small rods placed in their upper arm by a doctor or nurse which can prevent pregnancy for one or more years	Yes 1 No 2	Yes 1 No 2
Q32	CONDOM Men can put a rubber sheath on their penis before sexual intercourse	Yes 1 No 2	Yes 1 No 2
Q33	FEMALE CONDOM Women can place a sheath in their vagina before sexual intercourse	Yes 1 No 2	Yes 1 No 2
Q34	LACTATIONAL AMENORRHEA METHOD (LAM). After a mother has given birth, she breastfeeds exclusively so that she does not get pregnant for at least the first 6 months	Yes 1 No 2	Yes 1 No 2
Q35	RHYTHM METHOD Every month that a woman is sexually active she can avoid pregnancy by not having sexual intercourse on the days of the month she is most likely to get pregnant.	Yes 1 No 2	Yes 1 No 2
Q36	WITHDRAWAL Men can be careful and pull out before climax.	Yes 1 No 2	Yes 1 No 2
Q37	EMERGENCY CONTRACEPTION As an emergency measure after unprotected sexual intercourse, women can take special pills at any time within five days to prevent pregnancy.	Yes 1 No 2	Yes 1 No 2
Q38	Have you heard of any other ways or methods that women or men can use to avoid pregnancy?	Yes 1 Specify _____ No 2	Yes 1 No 2
Q39	Are you and your wife currently doing something or using any method to delay or avoid her getting pregnant?	Yes 1 No 2 →	GO TO Q43

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q40	Which method are you and/or your wife using? (IF MORE THAN ONE METHOD, CIRCLE ALL MENTIONED)	FEMALE STERILIZATION 1 MALE STERILIZATION 2 PILL 3 IUD 4 INJECTABLES 5 IMPLANTS 6 CONDOM 7 FEMALE CONDOM 8 DIAPHRAGM 9 FOAM/JELLY 10	

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
		LACTATIONAL AMEN	11	
		RHYTHM METHOD	12	
		WITHDRAWAL	13	
		Other……(SPECIFY)	14	
Q41	Where do you obtain (CURRENT METHOD) the last time? IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE _____ (NAME OF PLACE)	**PUBLIC SECTOR**		
		GOVT. HOSPITAL	1	
		GOVT. HEALTH CENTER	2	
		FAMILY PLANNING CLINIC	3	
		OUTREACH	4	
		GOVT COMMUNITY BASED DISTRIBUTOR	5	
		OTHER PUBLIC_____	6	
		PRIVATE MEDICAL SECTOR		
		PRIVATE HOSPITAL/CLINIC	7	
		PHARMACY/DRUG SHOP	8	
		PRIVATEDOCTOR/NURSE/MIDWIFE	9	
		OUTREACH	10	
		NGO COMMUNITY BASED DISTRIBUTOR	11	
		OTHER PRIVATE MEDICAL_____	12	
		OTHER SOURCE		
		SHOP	13	
		RELIGIOUS INSTITUTION	14	
		FRIEND/RELATIVE	15	
		Other	16	
Q42	Where would you prefer to obtain your method? _____ (NAME OF PLACE	**PUBLIC SECTOR**		SKIP TO Q46
		GOVT. HOSPITAL	1	
		GOVT. HEALTH CENTER	2	
		FAMILY PLANNING CLINIC	3	
		OUTREACH	4	
		GOVT COMMUNITY BASED DISTRIBUTOR	5	
		OTHER PUBLIC_____	6	
		PRIVATE MEDICAL SECTOR		
		PRIVATE HOSPITAL/CLINIC	7	
		PHARMACY/DRUG SHOP	8	
		PRIVATEDOCTOR/NURSE/MIDWIFE	9	
		OUTREACH	10	
		NGO COMMUNITY BASED DISTRIBUTOR	11	
		OTHER PRIVATE MEDICAL_____	12	
		OTHER SOURCE		
		SHOP	13	
		RELIGIOUS INSTITUTION	14	
		FRIEND/RELATIVE	15	
		Other	16	
Q43	Do you think you or your wife will use a contraceptive method to delay or avoid pregnancy at any time in the future?	Yes	1	
		No	2	
		Don't know	3	GO TO Q45
Q44	Which contraceptive method would you prefer to use?	FEMALE STERILIZATION	1	SKIP TO

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
		MALE STERILIZATION	2	Q46
		PILL	3	
		IUD	4	
		INJECTABLES	5	
		IMPLANTS	6	
		CONDOM	7	
		FEMALE CONDOM	8	
		DIAPHRAGM	9	
		FOAM/JELLY	10	
		LACTATIONAL AMEN	11	
		RHYTHM METHOD	12	
		WITHDRAWAL	13	
		Other……(SPECIFY)	14	
Q45	What is the main reason that you think you will not use a contraceptive method at any time in the future?	Not married	1	
		Fertility related reasons		
		Not having sex	2	
		Infrequent sex	3	
		My wife is menopausal/ or had a hysterectomy	4	
		Subfecund/infecund	5	
		Postpartum amenorrheic	6	
		Breastfeeding	7	
		Fatalistic	8	
		Opposition to use		
		Respondent opposed	9	
		Wife opposed	10	
		Others opposed	11	
		Religious prohibition	12	
		Lack of knowledge		
		Knows no methods	13	
		Knows no source	14	
		Method-related reasons		
		Health concerns	15	
		Fear of side effects	16	
		Lack of access/too far	17	
		Costs too much	18	
		Inconvenient to use	19	
		Interferes with body's normal processes	20	
		Other……	21	
		Don't know	98	
Q46	Did any health worker member at the health facility speak to you about family planning methods?	Yes	1	
		No	2	
Q47	Would you say that using contraception is mainly your decision, mainly your wife's decision, or did you both decide together?	Mainly respondent	1	
		Mainly wife	2	

No.	QUESTIONS AND FILTERS	CODING CATEGORY			SKIP
		Joint decision	3		
		Other(Specify)	6		
Q48	Do you think that taking contraception is a woman's responsibility, man's responsibility or both?	Woman's	1		
		Man's	2		
		Both woman's and man's responsibility	3		
		Other (Specify)	6		
Q49	How often have you talked to your wife about Family Planning in the past year?	Never	1		
		Once or twice	2		
		More often	3		
Q50	In the last six months have you seen or heard about family planning: a) On the radio? b) On the television? c) In a newspaper or magazine? d) On a sign or pamphlet? e) In a video or film?		Yes	No	
		Radio	1	2	
		Television	1	2	
		Newspaper/magazine	1	2	
		Sign or pamphlet	1	2	
		Video/film	1	2	

SECTION 4. FERTILITY PREFERENCES

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
ASK **A** OR **B** DEPENDING ON WHETHER HIS WIFE IS PREGNANT OR NOT				
A. WIFE NOT PREGNANT OR UNSURE:				
Q51	Now I have some questions about the future. Would you like to have a/another child or would you prefer not to have any (more) children?	Have a/another child	1	TO Q52
		No more/none	2	TO Q53
		Says his wife Can't get pregnant	3	TO Q59
		Undecided/don't know	4	TO Q54
Q52	IF RESPONDENT ANSWERS 1, ASK: **Why do you want** more children WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q53	IF RESPONDENT ANSWERS 2, ASK **Why don't** you want more children? WRITE EXACTLY WHAT THE RESPONDENT SAYS →			GO TO Q61
Q54	How long would you like to wait from now before the birth of a/another child?	Months	1	

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
		Years	2	
		Soon/now	3	
		Says his wife can't get pregnant	4	
		After marriage	5	
		Other (Specify) _____	6	
		Don't know	7	TO Q59
B. WIFE PREGNANT				
Q55	Now I have some questions about the future. After the child your wife is expecting now, would you like to have another child, or would you prefer not to have any more children?	Have a/another child	1	TO Q56
		No more/none	2	TO Q57
		Undecided/don't know	3	TO Q61
Q56	IF THE RESPONDENT ANSWERS 1, ASK: **Why do you want** more children WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q57	IF THE RESPONDENT ANSWERS 2, ASK: **Why don't** you want more children? WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q58	After the birth of the child your wife is expecting now, how long would you like to wait before the birth of another child?	Months	1	
		Years	2	
		Soon/now	3	
		After marriage	4	
		Other (Specify) _____	5	
		Don't know	6	
Q59	How many **more children** do you want to have?			
Q60	How many **more children** do you intend to have?			
Q61	Does your wife want **any more** children?	Yes	1	
		No	2	
		Don't know	3	
Q62	How **many more children** does she want to have? (WRITE THE NUMBER)			

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q63	How important is it to your wife to have **more** children?	Very Important 1 Important 2 Somewhat important 3 Not important 4 Don't know 5	
Q64	Does your wife want the same number of children that you want, or does she want more or fewer than you want?	Same number 1 More children 2 Fewer children 3 Don't know 4	
Q65	**THIS QUESTION SHOULD BE ASKED OF THOSE WHO DO NOT WANT A CHILD SOON OR DO NOT WANT ANY MORE CHILDREN BUT ARE NOT USING ANY FORM OF CONTRCEPTION I.E. THEY SAID NO TO QUESTIONS 39, 51 AND 55. ASK EITHER A OR B** **A. WANTS TO HAVE A/ANOTHER CHILD**: You have said that you do not want a/another child soon, but you are not using any method to avoid pregnancy. **OR** **B. WANTS NO MORE /NONE**: You have said that you do not want any (more) children, but you are not using any method to avoid pregnancy.		
	Can you tell me why you are not using a method? Any other reason? RECORD ALL REASONS MENTIONED.	Not married 1 **Fertility related reasons** Not having sex 2 Infrequent sex 3 My wife is menopausal/ or had a hysterectomy 4 Subfecund/infecund 5 Postpartum amenorrheic 6 Breastfeeding 7 Fatalistic 8 **Opposition to use** Respondent opposed 9 Wife opposed 10 Others opposed 11 Religious prohibition 12 **Lack of knowledge** Knows no methods 13 Knows no source 14 **Method-related reasons** Health concerns 15 Fear of side effects 16 Lack of access/too far 17 Costs too much 18 Inconvenient to use 19 Interferes with body's normal processes 20 Other…… 21	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Don't know 98	
Q66	**ASK EITHER A OR B** **A. HAS LIVING CHILDREN:** if you could go back to the time you did not have any children and could choose exactly the number of children to have in your whole life, how many would that be? **OR** **B. NO LIVING CHILDREN**: if you could choose exactly the number of children to have in your whole life, how many would that be?	None 1 Number ____ Other (specify) _____ 3	GO TO Section 5
Q67	How many of these children would you like to be boys, how many would you like to be girls and for how many would the sex not matter?	Boys / Girls / Either ____ / ____ / ____ Other (specify) _____	

SECTION 5. HIV KNOWLEDGE

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	Now I would like to ask to ask you some questions about AIDS		
Q68	Can the virus that causes AIDS be transmitted from a mother to her baby: a) During pregnancy? b) During delivery? c) By breastfeeding?		

	Yes	No	Don't know
During pregnancy	1	2	3
During delivery	1	2	3
Breastfeeding	1	2	3

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q69	Are there any special drugs that a doctor or a nurse can give to a woman infected with the AIDS virus to reduce the risk of transmission to the baby?	Yes 1 No 2 Don't know 3	TO Q72
Q70	Do you know of a place where a pregnant woman with the AIDS virus can go to get this drug to reduce the risk of her baby getting the AIDS virus?	Yes 1 No 2	TO Q72
Q71	Where is this place? PROBE: Any other place? PROBE TO IDENTIFY THE TYPE OF SOURCE AND CIRCLE THE APPROPRIATE CODES. IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE.	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	_____ (NAME OF PLACE/S)	PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14	
Q72	Have you heard about any drugs that people infected with the AIDS virus can get from a doctor or a nurse to help them live longer?	Yes 1 No 2 Don't know 3	TO SECTION 6
Q73	In the past six months, have you seen or heard anything about drug treatments for AIDS: a) On the radio? b) On the television? c) In a newspaper or magazine? d) On a sign or pamphlet? e) In a video or film?	Yes No Radio 1 2 Television 1 2 Newspaper or magazine 1 2 Sign or pamphlet 1 2 Video/film 1 2	
Q74	What drugs do you know about? PROBE: Any other drugs?	Antiretroviral drugs 1 Septrin 2 Other drugs (Specify)_____ 3 Don't know 4	
Q75	Do you know of a place to get Antiretroviral drugs?	Yes 1 No 2	TO Q77
Q76	Where is this place? PROBE: Any other place? PROBE TO IDENTIFY THE TYPE OF SOURCE AND CIRCLE THE APPROPRIATE CODE. IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE. _____ (NAME OF PLACE/S)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14	

No.	QUESTIONS AND FILTERS	CODING CATEGORY				SKIP
Q77	Now I'd like to ask you some questions about the Antiretroviral treatment (ART) that is available to people with AIDS virus. For each statement I read, please tell me if you agree or disagree with it a) ART is not a cure for the AIDS virus. b) A person receiving ART cannot transmit the virus to others c) Once ART is started, a patient must continue treatment for the rest of his/her life. d) People who know they are HIV positive should wait until they feel sick to see a doctor or nurse about ART. e) Failing to follow ART as directed can make the AIDS virus become stronger and even harder to control.		Agree	Disagree	Don't know	
		Cure	1	2	8	
		Transmit	1	2	8	
		Continue	1	2	8	
		Wait until	1	2	8	
		As directed	1	2	8	

SECTION 6. HIV HISTORY

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q78	When was your HIV diagnosis made?	Month ☐☐ Year ☐☐☐☐	
Q79	How long have you been attending this clinic?	Months ☐☐ Years ☐☐	
Q80	Are you presently taking Anti-retroviral therapy?	Yes 1	
		No 2 →	GO TO Q84
Q81	Which combination of Antiretroviral drugs are you taking?		
Q82	For how long have you been taking Antiretroviral therapy?	Months ☐☐ Years ☐☐	
Q83	Since you began to take Antiretroviral therapy, do you feel healthier?	Yes 1 No 2	
Q84	Are you currently taking Septrin?	Yes 1 No 2	
Q85	Have you disclosed your HIV status to your wife/wives?	Yes 1 No 2 Not applicable 3	
Q86	Have you disclosed you HIV status to your:	Yes / No Mother 1 / 2	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Mother-in-law 1 2 Children 1 2	
Q87	What is the HIV status of your wife?	Positive 1 Negative 2 Not applicable 3 Don't Know 4	
Q88	Is your wife taking Anti-retroviral therapy?	Yes 1 No 2 Not applicable 3 Don't Know 4	
Q89	Are any of your children HIV positive?	Yes 1 No 2 Not applicable 3 Don't Know 4	

SECTION 7. HIV/AIDS and Stigma

I'm going to read a list of events that may have happened to you during the past three months. After I read each item, please tell me how often it happened to you because of your HIV status:				
In the past 3 months, how often did the following events happen because of your HIV status?	Never	Once or twice	Several times	Most of the time
Q90. I was told to use my own eating utensils.	□	□	□	□
Q91. I was asked not to touch someone's child.	□	□	□	□
Q92. I was made to drink last from the cup.	□	□	□	□
Q93. Someone mocked me when I passed by.	□	□	□	□
Q94. I stopped eating with other people.	□	□	□	□
Q95. I was asked to leave because I was coughing.	□	□	□	□
Q96. Someone stopped being my friend.	□	□	□	□
Q97. A friend would not chat with me.	□	□	□	□

Q98. I was called bad names.	□	□	□	□
Q99. People sang offensive songs when I passed by.	□	□	□	□
Q100. I was told that I have no future.	□	□	□	□
Q101. Someone scolded me.	□	□	□	□
Q102. I was told that God is punishing me.	□	□	□	□
Q103. I was made to eat alone.	□	□	□	□
Q104. Someone insulted me.	□	□	□	□
Q105. People avoided me	□	□	□	□
Q106. People cut down visiting me	□	□	□	□
Q107. People ended their relationships with me	□	□	□	□
In the past 3 months, how often did the following events happen because of your HIV status?	Never	Once or twice	Several times	Most of the time
Q108. I was blamed for my HIV status	□	□	□	□
Q109. Someone tried to get me fired from my job.	□	□	□	□
Q110. My employer denied me opportunities.	□	□	□	□
The next set of questions is about your experiences in the hospital or clinic.				
In the past 3 months, how often did the following events happen because of your HIV status?	Never	Once or twice	Several times	Most of the time
Q111. I was denied health care.	□	□	□	□
Q112. I was refused treatment because I was told I was going to die anyway.	□	□	□	□
Q113. I was discharged from the hospital while still needing care.	□	□	□	□
Q114. I was shuttled around instead of being helped by a nurse.	□	□	□	□
Q115. At the hospital/clinic, I was made to wait until last	□	□	□	□
Q116. At the hospital, I was left in a soiled bed.	□	□	□	□
Q117. In the hospital or /clinic, my pain was ignored.	□	□	□	□

These questions are about some of your thoughts or feelings.				
How often have you thought or felt this way during the past 3 months because of your HIV status?	Never	Once or twice	Several times	Most of the time
Q118. I felt that I did not deserve to live.	□	□	□	□
Q119. I felt ashamed of having this disease.	□	□	□	□
Q119. I felt completely worthless.	□	□	□	□
Q120. I felt that I brought a lot of trouble to my family.	□	□	□	□
Q121. I felt that I am no longer a person.	□	□	□	□

THANK YOU FOR PARTICIPATING IN THIS INTERVIEW.

APPENDIX 8: Men's questionnaire (Luo)

MEN'S QUESTIONNAIRE (LUO)

LAPENY PA COO **Questionnaire ID _____**

Nino me interview_____ **Nying lapeny_____**

Lep ma ki tiyo kede i peny man_____

Instructions to Interviewer: CIRCLE THE CODE NUMBER NEXT TO THE ANSWER GIVEN

SECTION 1. RESPONDENT'S BACKGROUND

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q1	COO NYO MON	Male 1 Female 2	
Q2	I Bedo Kwene? Caaro :_____ Parish:_____ Sub county:_____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q3	Iri Kany pi kare marom mene	Years ☐☐ Always 95 Visitor 96	→ GO TO Q5
Q4	Nongo lbedo kwene mapud pe kobo kanya Kabedo: _____	Town 1 Trading centre 2 Village 3 IDP camp 4 Other 5	
Q5	Nino mene, Dye mene kede mwaka mene ma kinwalo iye ?	Day ☐☐ Month ☐☐ Year ☐☐☐☐	
Q6	Mwaki ni adi ?	Years old ☐☐ (Age completed in years) CROSS-CHECK WITH DATE OF BIRTH AND RECONCILE	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q7	Ono Itemo kwan?	Yes 1 No 2 →	GO TO Q10
Q8	Rwom kwani ogik kwene? (CIRCLE HIGHEST SCHOOL LEVEL)	Primary 1 'O" level 2 'A' level 3 Tertiary 4 University 5	
Q9	I gik i kilaaci adi?	Class/Year ☐☐	
Q10	Dini ni aye mene?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6 Other……(SPECIFY) 7	
Q11	Itiyo tic ango? _____	Not employed 1 Business 2 Police/military 3 Student 4 Farmer 5 Housewife 6 Professional 7 Other…… 8	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q12	Inyome?	Single/never married 1 → Married 2	GO TO SECTION 2

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Cohabiting 3 Widowed 4 Divorced 5 Separated 6 Other…… 7	
Q13	I tye ki dako onyo mon mukene ma i bedo kwedgi?	Yes 1 No 2 →	GO TO Q15
Q14	I tye ki mon adi?	☐☐	If more than one wife go to Q21
Q15	Dako ni tye ki mwaka addi?	Years old ☐☐ (Age completed in years)	
Q16	Dako ni okwano?	Yes 1 No 2 ⇒ Don't know 3 →	GO TO Q19
Q17	Rwom kwan ne ogik kwene?	Primary 1 'O" level 2 'A' level 3 Tertiary 4 University 5 Don't know 6 →	GO TO Q19
Q18	Dako ni ogik i kilaaci adi?	Class/Year ☐☐ Don't Know 9	
Q19	Dako ni lubo dini mene?	None 1 Catholic 2 Protestant 3 Muslim 4 Pentecostal 5 SDA 6	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Other (Specify) _____ 7	
Q20	Dako ni tiyo tic ango? _____	Not employed 1 Business 2 Police/military 3 Student 4 Farmer 5 Housewife 6 Professional 7 Other…… 8	

Q21. IF MORE THAN ONE WIFE (use the same codes as above):

Dako me adi?	Mwaka ne	Okwano?	ogik i kilaaci adi?	Dini	tiyo tic ango?	Lutino adi ki dako man?	Kombedi Oyac?	Yic dong dwe adi?
1								
2								
3								
4								
5								
6								
7								
8								

SECTION 2. REPRODUCTION

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIPv
Q22	Kumbedi amiro penyo lok ikom lutino mo kiken ma inwyalo ikwoni. Ya inwyalo latin mo ki dako mo kiken?	Yes 1 No 2 Don't know 3 → GO TO SECTION 3	
Q23	Kumbedi amiro penyo lok ikom lutino mo kiken ma inwyalo ikwoni. Ya inwyalo latin mo ki dako mo kiken?	☐☐	
Q24	Dong amito cooyo lok kum lutino ma inywalo, ma kwo ki mutoo, caako ki latin me acel		

Latin me adi?	Latin awobi onyo nyako	Latin kwo?	Mwaka pa latin	Ka oto,nyo tye ki mwaka adi?	Ngo ma Oneko?
Me Acel	Awobi 1 Anyaka 2	Yes 1 No 2 →			
Me ariyo	1 Awobi Anyaka 2	Yes 1 No 2 →			
Me adek	Awobi 1 Anyaka 2	Yes 1 No 2 →			
Me angwen	Awobi 1 Anyaka 2	Yes 1 No 2 →			
Me abic	Awobi 1 Anyaka 2	Yes 1 No 2 →			
Me abicel	Awobi 1 Anyaka 2	Yes 1 No 2 →			
IF MORE THAN 6 CHILDREN USE AN EXTRA SHEET					

SECTION 3. CONTRACEPTION

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q25	Kombedi amito lok I kom Lago kin nywal – yoo mapat-pat ma laco ki dako twero tic kwede me lago onyo juku nywal FOR METHODS NOT MENTIONED SPONTANEOUSLY, ASK: Have you ever heard of (METHOD)? CIRCLE CODE 1 FOR EACH METHOD MENTIONED SPONTANEOUSLY. THEN PROCEED DOWN COLUMN, READING THE NAME AND DESCRIPTION OF EACH METHOD NOT MENTIONED SPONTANEOUSLY. CIRCLE CODE 1 IF METHOD IS RECOGNIZED, AND CODE 2 IF NOT RECOGNIZED. THEN, FOR EACH METHOD WITH CODE 1 CIRCLED IN A, ASK B.	**A**	**B**: In onyo dako otiyo ki yoo magi?
Q26	Dako romo nongo ayango manok ci tweyo ocike ma kelo tonge ci dong pe binongo latin matwal	Yes 1 No 2	Yes 1 No 2
Q27	Laco romo nongo ayango manok ci tweyo ocike ma kelo lac co ci pe romo nywalo latin mo keken		In dong inongo ayango man pe me nongo dok lutino mukene?

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Yes 1 No 2	Yes 1 No 2
Q28	Dako twero mwonyo yat nino ducu ci pe yac	Yes 1 No 2	Yes 1 No 2
Q29	dako romo tic ki waya ma orine ma ki kiketo i ot nyodo ki ot yat me juku yaco	Yes 1 No 2	Yes 1 No 2
Q30	Dako twero nongo libira ki bot lutic I ot yat me juko nyodo pi dwe acel onyo ma kato	Yes 1 No 2	Yes 1 No 2
Q31	Dako twero nongo yat makirwako ibade ki bot daktar me juku nyodo pi dwe acel onyo ma kato	Yes 1 No 2	Yes 1 No 2
Q32	Coo twero ruko roc bol (Kondom) ikome me coo ma poya obutu ki dako	Yes 1 No 2	Yes 1 No 2
Q33	Dako twero kero roc bol (kondom) ikome me mon ma poya obutu ki laco	Yes 1 No 2	Yes 1 No 2
Q34	LACTATIONAL AMENORRHEA METHOD (LAM). Ki inge nyal, Doto Latin pi kare malac gengo gamo yic pi dwe abicel onyo ma caro	Yes 1 No 2	Yes 1 No 2
Q35	RHYTHM METHOD Dwe ki dwe dako ma rwate ki cware twero lago nyodo ka pe butu ki cware ikare ma en ngeyo ni eromo yac iye.	Yes 1 No 2	Yes 1 No 2
Q36	WITHDRAWAL Laco twero gwoke ka wote dako ma nongo peya olaya lac pa coo	Yes 1 No 2	Yes 1 No 2
Q37	EMERGENCY CONTRACEPTION Ki inge butu ki laco, dako romo munyo yat ma kiyubu me juku gamo yic inino abic.	Yes 1 No 2	Yes 1 No 2
Q38	Dong iwinyo pi yo mukene ma dako romo tic kwede me juku gamo yic?	Yes 1 Specify _____ No 2	Yes 1 No 2
Q39	Kombedi itye katimu gimoo onyo tic ki yoo mukene me galu nyo juku gamo yic?	Yes 1 No 2 →	GO TO Q43

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q40	Yo mene ma i tye ka tic kede ki dako ni? (IF MORE THAN ONE METHOD, CIRCLE ALL	FEMALE STERILIZATION 1 MALE STERILIZATION 2	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	MENTIONED)	PILL 3 IUD 4 INJECTABLES 5 IMPLANTS 6 CONDOM 7 FEMALE CONDOM 8 DIAPHRAGM 9 FOAM/JELLY 10 LACTATIONAL AMEN 11 RHYTHM METHOD 12 WITHDRAWAL 13 Other……(SPECIFY) 14	
Q41	Igamo ki ot yat onyo kabedo mene? IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE _____ (Nying kabedo)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED DISTRIBUTOR 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 NGO COMMUNITY BASED DISTRIBUTOR 11 OTHER PRIVATE MEDICAL_____ 12 **OTHER SOURCE** SHOP 13 RELIGIOUS INSTITUTION 14 FRIEND/RELATIVE 15 Other 16	
Q42	Kwene ma no imito gamo ki ye? _____ (Nying kabedo)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED DISTRIBUTOR 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 NGO COMMUNITY BASED DISTRIBUTOR 11 OTHER PRIVATE MEDICAL_____ 12 **OTHER SOURCE**	

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
		SHOP	13	
		RELIGIOUS INSTITUTION	14	
		FRIEND/RELATIVE	15	
		Other	16	
Q43	Itamo ni in onyo dako ni bi tiyo ki yo mo me galo nyo gengo gamo yic ayim?	Yes	1	
		No	2	
		Don't know	3	GO TO Q49
Q44	Yo mene ma imito tic kwede?	FEMALE STERILIZATION	1	GO TO Q50
		MALE STERILIZATION	2	
		PILL	3	
		IUD	4	
		INJECTABLES	5	
		IMPLANTS	6	
		CONDOM	7	
		FEMALE CONDOM	8	
		DIAPHRAGM	9	
		FOAM/JELLY	10	
		LACTATIONAL AMEN	11	
		RHYTHM METHOD	12	
		WITHDRAWAL	13	
		Other……(SPECIFY)	14	
Q45	Ngo ma genyi tic ki yo mo kiken me galo onyo gengo gamo yic?	Not married	1	
		Fertility related reasons		
		Not having sex	2	
		Infrequent sex	3	
		My wife is menopausal/ or had a	4	
		Subfecund/infecund	5	
		Postpartum amenorrheic	6	
		Breastfeeding	7	
		Fatalistic	8	
		Opposition to use		
		Respondent opposed	9	
		Wife opposed	10	
		Others opposed	11	
		Religious prohibition	12	
		Lack of knowledge		
		Knows no methods	13	
		Knows no source	14	
		Method-related reasons		
		Health concerns	15	
		Fear of side effects	16	
		Lack of access/too far	17	
		Costs too much	18	
		Inconvenient to use	19	
		Interferes with body's normal processes	20	
		Other……	21	

No.	QUESTIONS AND FILTERS	CODING CATEGORY			SKIP
		Don't know	98		
Q46	Dactar oloko kedi ikom yo ma pat pat mi Lago nywal?	Yes	1		
		No	2		
Q47	Anga ma yero yo ma otiyo kede me galo nyo gengo gamo yic? yin, dako, kede won ariyo wen?	Mainly respondent	1		
		Mainly husband/partner	2		
		Joint decision	3		
		Other(Specify)	6		
Q48	Tic ki yo mo me galo nyo gengo gamo yic tye I twero pa anga? Dako, Laco, kede gin ariyo weng?	Woman's	1		
		Man's	2		
		Both woman's and man's responsibility	3		
		Other (Specify)	6		
Q49	Iloko ki Dako ni kidi i mwaka mukaro ikom Lago kin nywal?	Never	1		
		Once or twice	2		
		More often	3		
Q50	Ikin dwe abicel mukaro iwinyo pi Lago kin nywal: a) ki iredio? b) ki T.V? c) ki gajeti onyo karatac akwana? d) i sign post onyo waraga? e) i video/cinema		Yes	No	
		Radio	1	2	
		Television	1	2	
		Newspaper/magazine	1	2	
		Sign or pamphlet	1	2	
		Video/film	1	2	

SECTION 4. FERTILITY PREFERENCES

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
ASK **A** OR **B** DEPENDING ON WHETHER HIS WIFE IS PREGNANT OR NOT				
A. WIFE NOT PREGNANT OR UNSURE:				
Q51	Kombedi amito penyi peny me kwo ni ma anyim. Imito lutino mukene?	Have a/another child	1	TO Q52
		No more/none	2	TO Q53
		Says his wife Can't get pregnant	3	TO Q59

No.	QUESTIONS AND FILTERS	CODING CATEGORY		SKIP
		Undecided/don't know	4	TO Q54
Q52	IF RESPONDENT ANSWERS 1, ASK: Pingo imito lutino mukene? WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q53	IF RESPONDENT ANSWERS 2, ASK **Pingo pi imito lutino?** WRITE EXACTLY WHAT THE RESPONDENT SAYS →			GO TO Q61
Q54	I bi kuru pi kara ma rom kwene me nongo latin mukene?	Months	1	
		Years	2	
		Soon/now	3	
		Says his wife can't get pregnant	4	
		After marriage	5	
		Other (Specify) _____	6	
		Don't know	7	TO Q59
B. WIFE PREGNANT				
Q55	Kombedi amito penyi peny me kwo ni ma anyim. Ki enge latin man ma tye i yic, imito latin mukene, kede dong ideg lutino mukene?	Have a/another child	1	TO Q56
		No more/none	2	TO Q57
		Undecided/don't know	3	TO Q61
Q56	IF THE RESPONDENT ANSWERS 1, ASK: **Pingo imito lutino mukene?** WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q57	IF THE RESPONDENT ANSWERS 2, ASK: **Pingo pi mito lutino mukene?** WRITE EXACTLY WHAT THE RESPONDENT SAYS →			
Q58	Ka dako ni onywal, i bi kuru pi kara ma rom kwene me nongo latin mukene?	Months	1	
		Years	2	
		Soon/now	3	
		After marriage	4	
		Other (Specify) _____	5	
		Don't know	6	
Q59	Imito lutino adi?			

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q60	Imito medo lutino adi?		
Q61	Dako ni mito lutino mukene?	Yes 1 No 2 Don't know 3	
Q62	Dako ni Mito Lutino adi?		
Q63	Pire tek ki bot dako ni omed lutino mukene?	Very Important 1 Important 2 Somewhat important 3 Not important 4 Don't know 5	
Q64	Dako ni mito wel Lutino ma yin bene imito kede omito ma pat pat?	Same number 1 More children 2 Fewer children 3 Don't know 4	
Q65	**THIS QUESTION SHOULD BE ASKED OF THOSE WHO DO NOT WANT A CHILD SOON OR DO NOT WANT ANY MORE CHILDREN BUT ARE NOT USING ANY FORM OF CONTRCEPTION I.E. THEY SAID NO TO QUESTIONS 39, 51 AND 55. ASK EITHER A OR B** **A. WANTS TO HAVE A/ANOTHER CHILD**: I waki pi mito Latin mukene oyot yot ento pi tye ka tic ki yo mo me gengo gamo yic? **OR** **B. WANTS NO MORE /NONE**: I waki dong pe mito Lutino mukene ento pi tye ka tic ki yo mo me gengo gamo yic?		
	Pingo I pe ka tic ki yo mo me gengo nywal? RECORD ALL REASONS MENTIONED.	Not married 1 **Fertility related reasons** Not having sex 2 Infrequent sex 3 My wife is menopausal/ or had a hysterectomy 4 Subfecund/infecund 5 Postpartum amenorrheic 6 Breastfeeding 7 Fatalistic 8 **Opposition to use** Respondent opposed 9 Wife opposed 10 Others opposed 11 Religious prohibition 12 **Lack of knowledge**	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		Knows no methods 13 Knows no source 14 **Method-related reasons** Health concerns 15 Fear of side effects 16 Lack of access/too far 17 Costs too much 18 Inconvenient to use 19 Interferes with body's normal processes 20 Other…… 21 Don't know 98	
Q66	**ASK EITHER A OR B** **A. HAS LIVING CHILDREN:** Ka nene iromo dok cen ikare ma peya onongo itye ki lotino mo keken, ka iromo cimo wel litino adi ma onongo ibimito? **OR** **B. NO LIVING CHILDREN**: **:** Ka iromo cimo wel litino ma imito ikwo ni kikome, onongo icimo adi?	None 1 Number Other (specify) _____ 3	GO TO Section 5

Q67	Onongo imiti Anyira kubed adi? Awobi adi? Adi ma onongo pe iparo ka nyaka nyo awobi?	Boys	Girls	Either	
		Other (specify) _____			

SECTION 5. HIV KNOWLEDGE

No.	QUESTIONS AND FILTERS	CODING CATEGORY			SKIP
	Kombedi amito penyo in ikom two Jonyo				
Q68	Kudi me two jonyo twero kobi Latin ki bot min ne? a) Ma Pud oyac? b) Ka nywal? c) Ka dot latin?		Yes	No	Don't know
		During pregnancy	1	2	3
		During delivery	1	2	3
		Breastfeeding	1	2	3
Q69	Yat mo tye ma dactari miyo ki min latin mi temo gengo two man mi kobi Latin?	Yes 1 No 2 Don't know 3			TO Q72
Q70	I ngeyo kabedo mo ma mon mu yac gamo yat man ki ye?	Yes 1 No 2			TO Q72
Q71	Kwene? PROBE: Kabedo mukene tye? PROBE TO IDENTIFY THE TYPE OF SOURCE AND CIRCLE THE APPROPRIATE CODES. IF UNABLE TO DETERMINE IF HOSPITAL,	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3			

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
	HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE. _____ (NAME OF PLACE/S)	OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7 PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14	
Q72	I winyo pi yat mo ma kimiyo ki Lutwo Cilim me medo kwogi?	Yes 1 No 2 Don't know 3 →	TO SECTION 6
Q73	I dwe abicel mukaro, iwinyo pi yadi nyo ineno yadi me konyo lutwo Jonyo? a) ki iredio? b) ki T.V? c) ki gajeti onyo karatac akwana? d) i sign post onyo waraga? e) i video/cinema	Yes No Radio 1 2 Television 1 2 Newspaper or magazine 1 2 Sign or pamphlet 1 2 Video/film	
Q74	Yadi mene ma ingeyo me konyo lutwo Jonyo? PROBE: Yat Mukene tye?	Antiretroviral drugs 1 Septrin 2 Other drugs (Specify)_____ 3 Don't know 4	
Q75	I ngeyo kabedo ma kigamo yadi man ki ye?	Yes 1 No 2 →	TO Q77
Q76	Yadi man kigamo ki kwene? PROBE: Kabedo mukene tye? PROBE TO IDENTIFY THE TYPE OF SOURCE AND CIRCLE THE APPROPRIATE CODE. IF UNABLE TO DETERMINE IF HOSPITAL, HEALTH CENTER, VCT CENTER, OR CLINIC IS PUBLIC OR PRIVATE MEDICAL, WRITE THE NAME OF THE PLACE. _____ (NAME OF PLACE/S)	**PUBLIC SECTOR** GOVT. HOSPITAL 1 GOVT. HEALTH CENTER 2 FAMILY PLANNING CLINIC 3 OUTREACH 4 GOVT COMMUNITY BASED WORKER 5 OTHER PUBLIC_____ 6 **PRIVATE MEDICAL SECTOR** PRIVATE HOSPITAL/CLINIC 7	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
		PHARMACY/DRUG SHOP 8 PRIVATEDOCTOR/NURSE/MIDWIFE 9 OUTREACH 10 TASO 11 AIDS INFORMATION CENTRE 12 **OTHER PRIVATE/NGO MEDICAL (Specify)** 13 Other (Specify) _____ 14	
Q77	Kombedi amito penyo in ikom yadi ma kitiyo kede me konyo jo ma tye ki two Jonyo. Amiti iwaca ka iyee kede pi yee lok ma bi titi. a) Yat ART pee cango two jonyo. b) Ngat ma munyo yat man pi kobo two bot ngat mukene. c) Ka ikyako tic kede, pi dong igiko ma twal. d) Jo ma gin ngeyo ni gin tye ki two jonyo myet gin okuu ka gin minyo kom gi lit yaka kun en dactar pi yat man. e) Munyo yat man I yoo mu poke ki ma dactari owacu medo two ameda dok bene weko yat pi tiyo mabe	Agree / Disagree / Don't know Cure: 1 / 2 / 8 Transmit: 1 / 2 / 8 Continue: 1 / 2 / 8 Wait until: 1 / 2 / 8 As directed: 1 / 2 / 8	

SECTION 6. HIV HISTORY

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q78	I ngeyo pi two man(jonyo) awene?	Month ☐☐ Year ☐☐☐☐	
Q79	Dong ibino i ot yat kany pi kare marom kwene?	Months ☐☐ Years ☐☐	
Q80	Itye ka munyo Yat me two jonyo(ARVs)?	Yes 1 No 2 →	 GO TO Q84
Q81	Itye ka munyo Yadi mene?		
Q82	Dong imunyo yadi man pikare ma rom kwene?	Months ☐☐ Years ☐☐	
Q83	Aloka loka obedo tye ma icako tic ki Yadi mi two Jonyo?	Yes 1 No 2	
Q84	I munyo Septrin?	Yes 1 No 2	
Q85	Iniango Dako ni ni itye ki two jonyo onyo I pe kwede?	Yes 1 No 2 Not applicable 3	

No.	QUESTIONS AND FILTERS	CODING CATEGORY	SKIP
Q86	Iwaco ni itye ki two jonyo onyo pod pya I waco bot:	Yes / No Mother 1 2 Mother-in-law 1 2 Children 1 2	
Q87	Dako ni tyeki two jonyo onyo pe kwede?	Positive 1 Negative 2 Not applicable 3 Don't Know 4	
Q88	Dako ni tye ka mwonyo yat lajing two jonyo?	Yes 1 No 2 Not applicable 3 Don't Know 4	
Q89	Latini mo tye ki two jonyo?	Yes 1 No 2 Not applicable 3 Don't Know 4	

SECTION 7. HIV/AIDS and Stigma

Abe kwano jami magi ma i kare mogo gwok otimme i komi i dwe adek mukato ni. Ka akwano gi, wacca, tyen adi ma otimme i komi pi lok kom two jonyo

I dwe Adek mukato ni, jami magi otimme I komi tyen adi?	pe otimme matwal	tyen acel onyo aryo	tyen madwong	kare ducu
Q90. Ki wacca ni atii ki jami cam ma mega	□	□	□	□
Q91. Ki wacca ni pe agud latin pa ngat mo	□	□	□	□
Q92. Ki weko an aye agiko mato pii kii i kikopo	□	□	□	□
Q93. Dano nyero an ka atye ka kato	□	□	□	□
Q94. A jukku cam ki dano	□	□	□	□
Q95. Ki ryema woko pien atye ka oono	□	□	□	□
Q96.Ngat mo ojukku bedo larema	□	□	□	□

Q97. Larema pe book lok ki an	□	□	□	□
Q98. Ki lwongo an ki nying ma raco	□	□	□	□
Q99. Dano owero wer marac ka atye ka kato	□	□	□	□
Q100. Ki wacca ni anyimma cok	□	□	□	□
Q101. Ngat mo odaa ki an	□	□	□	□
Q102.Ki wacca ni Rubanga tye ka pwodda	□	□	□	□
Q103. Ki weko acamo kena	□	□	□	□
Q104. Ngat mo oyeto an	□	□	□	□
Q105. Dano oweko an	□	□	□	□
Q106. Dano oweko limo an	□	□	□	□
Q107. Dano opokke ki an	□	□	□	□
I dwe Adek mukato ni, jami magi otimme I komi tyen adi?	pe otimme matwal	otimme tyen acel onyo aryo	otimme tyen mapol	otimme kare ducu
Q108. Ki wacco ni atimo bal pi nongo two jonyo	□	□	□	□
Q109. Ki temo ryemma ki i dog tic	□	□	□	□
Q110. Ladit tic okwero meddo rwom me ticca malo	□	□	□	□
Lapeny magi tye pi gin ma otimme i komi ki i ot yat				
I dwe Adek mukato ni, jami magi otimme I komi tyen adi?	pe otimme matwal	otimme tyen acel onyo aryo	otimme tyen mapol	otimme kare ducu
Q111. Pe ki miyo bot an kony	□	□	□	□
Q112. Pe ki miyo yat bot an pien ki wacca ni pud abe too woko	□	□	□	□
Q113. Ki kwanya ki i ot yat ma pud amito kony	□	□	□	□
Q114. Nurse obedo ka jungu an, labongo miyo kony	□	□	□	□
Q115.ki weko abedo ngat me agikki ki i ot yat	□	□	□	□
Q116. Ki weko a butu i wi kitanda ma col ki i ot yat	□	□	□	□
Q117. I ot yat, pe ki paro pi arem ma mega	□	□	□	□
Lapeny mago tye pi tam ni ki kit ma iwinyo kwede				
I winyo kuman tyen adi i dwe 3 ma okato ni pi lok me two jonyo ni?	pe awinyo matwal	kicel onyo kiryo	tyen mapol	I kare ducu
Q118. Atamo ni omyero atoo woko	□	□	□	□

Q119. Lewic omaka pi bedo ki two jonyo	□	□	□	□
Q120. Anongo ni konya peke	□	□	□	□
Q121. Anongo ni akelo peko mapol i gang wa	□	□	□	□
Q122. Anongo ni an dong pe adano.	□	□	□	□

APWOYO BEDO I LAPENY MAN

APPENDIX 9: Semi-structured interview schedule (English)

Semi-structured Interview Schedule (English)

Introduction:

Thank you for your willingness to participate in this study and to be interviewed. I am interested in looking at desires for children among PLWHA. You have been particularly chosen because I hope you will be able to share your experiences of with me and what having children means for you, your spouse and family. We will start by asking you some general questions about yourself and your family. I know that some of the questions are about matters that might be upsetting for you so if there are any questions that you don't want to answer, please just say so and we will go on to the next question. However your honest answers to these questions will help us to better understand how PLWHA feel about having children and the better ways in which health workers can support you and others.

Date of interview…/…/… Name of interviewer……Language of interview……...

A. Background and demographics

- Gender and age
- Religion
- Languages spoken and understood
- Previous education

B. General questions

- For long have you known that you have HIV/AIDS?
- Does your spouse know your status?
- Do other family members know your HIV status?
- How many children do you have?
- Have you had children ever since you were told you have HIV?

C. Theme: Motherhood/Fatherhood

- In general, how do you feel about being a mother/father?

D. Theme: Childbearing

- What do you feel about having children?
- Are they an important part of your life? Please explain
- Are children an important part of your spouses' life? Please explain
- Are children important for the family, the clan, the tribe? Please explain
- Can you tell me why you might want to become pregnant despite being HIV positive?
- You have had a pregnancy since you were diagnosed with HIV. Can you describe your feelings about the pregnancy, from the time of conception to delivery? Tell me about the feelings of others like your husband, your mother and other family members.
- Did you decide to get pregnant? If so, why did you decide to get pregnant?
- Did you feel any hostility from health workers when you were pregnant?
- Has your HIV status affected your thoughts about having children?
- Do you think you would feel differently if you didn't have HIV?
- What are the most important things you think about when you think about having children?
- Have you heard of any other HIV positive person becoming pregnant? What were your thoughts?
- How do you feel about having more children now that you know that you are HIV positive?
- How does your husband/mother/family feel about you having more children now that he/she/they know that you are HIV positive?
- Are you worried about your own health?
- Are you worried that pregnancy may negatively affect your health?

E. Theme: Impact of availability of PMTCT and ART programs on fertility choices

- Do you know where you can get treatment to prevent AIDS transmission from a mother to her child?
- If you could get these services would you think about having a child?
- If you could get antiretrovirals (yat me two jonyo) would you think about having a child again?

F. Theme: Experiences of family planning service provision and its impact on fertility decisions

- Please tell me about any experiences you have had of accessing Family planning services in Gulu?

- Have you been able to access family planning services in Gulu?
- Have you had any difficulties accessing family planning services in Gulu?
- Has any health worker ever had any discussions with you about family planning?
- Do you have any suggestions on how family planning services in Gulu can be improved?

G. Theme: Experiences of HIV stigma and its impact on fertility decisions

- Have you had any negative comments from family, friends or health workers when you decided to become pregnant?
- Have you heard of any negative comments from family, friends or health workers when the other HIV positive person decided to become pregnant? How did you feel about it?

H. Theme: Influence of family, friends, society, medical personnel, community perceptions towards individual's child bearing desires

- Have you had discussions with your spouse about having children?
- Have you had family discussions about having children?
- Do family members encourage or discourage you from having children?
- Have you had any discussions with a health worker about your desires to have children?

I. Theme: The impact of the prolonged civil conflict in their reproductive decisions

- How do you think this war has affected the thoughts of the people in this region towards having children?
- How has the war affected the people's thoughts towards family planning?

Thank you for having this detailed conversation with me. Do you have any questions for me?
Is there anything about this study you would like to know?
Is there anything else you would like to know?

APPENDIX 10: Semi-structured interview schedule (Luo)

Semi-structured Interview Schedule (Luo):
Introduction:
Apwoyo yee gamo peny man I purujeki ni. Ayeri piyen amito ngec ma lube ki miti me nongo lutino ki bot yin, dakoni/cwari ki jo ot ni.. A bi cyako ki penyo yin ikom kwoni ki pa jo ot ni. Lapeny mukene obigudu tam ma i cwinyi, itwero yero mi pe gamogi ka onyo itamo ni lagam meno bicwero cwinyi. Itwero yero me giko gamo lapeny mo keken onyo weng i cawa mo keken kadi wa inge peny man ento ma peya repot me purujeki otum. Kony ma megi i purujek man obi konyo wan matek mi ngeno miti me nongo lutino ikin jo ma tye ki two jonyo ki kit ma lutic ot yat twero konyo yin ki jo mukene.

Nino me interview…/.../... **Nying lapeny…….**

Lep ma ki tiyo kede i peny man……..

J. Background and demographics
- Coo nyo mon ki mwaka
- Dini
- Lep ma ki nyang ki ma ki loko
- Kwan

K. General questions
- Pi kara ma rom kwene ma dong ingeyo ni itye ki two jonyo?
- Won ot ti (Cwari)/ Min ot ti (Dako ni) ngeyo pi two ni man?
- Jo ot ni mukene ngeyo pi two ni man?
- Itye ki lutino adi?
- Ki nge ngeno ni itye ki two jonyo, inywalo lutini mukene?

L. Theme: Motherhood/Fatherhood
- I tamo ni ango ikom bedo min lutino/won lutino?

M. Theme: Childbearing
- Tami ngo ikom nywalo lutino?
- Pii gi tek I kwo ni? Tita pingo ne.
- Pii gi tek I kwo pa cwari? Tita pingo ne.
- Pii gi tek I kin jo ot ni, I kin gang, I kaka?
- I twero waca pingo imito yac kede ingeyo ni itye ki two?
- Iyac ma onongo dong ingeyo ni itye ki two jonyo. Tita tam ni ikom yaco ni ki acaki ne naka ikom nywal. Tam pa jo mukene kono? Cwari, mamani, jo ot ni mukene, Did you decide to get pregnant? If so, why did you decide to get pregnant?
- Lutic i ot yat gin otiyo ikomi ma rac ma onongo yii tye.
- Two ni oloko cwinyi ikom nywal?
- Itamo ni cwinyi onongo loke ko onongo ipe ki two man?
- Ngo ma pire tek tutwal ka itamo pi lutino?
- Iwinyo pi dako mo ma oyac ki onongo tye ki two jonyo? Itamo ni ngo?
- Itamo ni ngo pi nywalo lutino mukene kombedi ma dong ingeyo ni itye ki two jonyo?
- Cwari/mama ni/ jo ot ni tamo ni ngo pi nywalo lutino mukene kombedi ma dong gin ngeyo ni itye ki two jonyo?
- Iparo pi yot kom ni?
- Iparo ni yacoo obi balo yot kom ni?

N. Theme: Impact of availability of PMTCT and ART programs on fertility choices

- In ngeyo ni itwero gamo yat me gengo kobo two ki kom mine bot?
- If you could get these services would you think about having a child?
- Ka itwero nongo yat me two jonyo, imito lutino mukene?

O. Theme: Experiences of family planning service provision and its impact on fertility decisions

- Tim be i waca pi kare ma iciro ka nongo kony mi lago kin nywal i Gulu?
- I gamo kony me lago kin nywal ki Gulu?
- Ino ayela mo ka gamo kony man i Gulu?
- Dactari mo ya oloko kedi ikom lago kin nywal?
- Itye ki tam mo ma onongo jo ma gin miyo kony man i Gulu onongo gi twero timo mi medo tic gi?

P. Theme: Experiences of HIV stigma and its impact on fertility decisions

- Dano oloko marac ikomi ma iwaci in imito yac ki latin mukene? Cwari/mama ni/ jo ot ni/ luremi ?
- I winyo dano ka gi loko marac ikom jo mukene ma tye ki two jonyo ki gin oyac? Cwari/mama ni/ jo ot ni/ luremi? In itamo ningo ?

Q. Theme: Influence of family, friends, society, medical personnel, community perceptions towards individual's child bearing desires

- Iloko ki cwari/dako ni pi nywalo lutino?
- Iloko ki jo ot ni pi nwalo lutino?
- Jo ot ni miti inywal lutino?
- Iloko ki dactari pi miri ni me nywalo lutino?

R. Theme: The impact of the prolonged civil conflict in their reproductive decisions

- Lweng man oloko tam pa dano ma kan ikom nywal?
- Lweng man oloko tam pa dano ni ni?

Apwoyo lok keda ki gamo peny man. Itye ki peny mo ma imito penyo an? Tye gin mo ikom kwan man ma imito ngeno ne? Tye gin mo mukene ma imito ngeno?

APPENDIX 11: Question guide for Ministry of Health, WHO, UNICEF, UNFPA officials

QUESTION GUIDE FOR MINISTRY OF HEALTH OFFICIALS, WHO, UNICEF, UNFPA UGANDA

Questions:

1. Does the Ministry of Health have an official policy on the integration of Family planning services with HIV services?
2. Does the Ministry of Health provide written or verbal guidelines on the integration of Family planning services with HIV services?
3. Are these guidelines separate or integrated with VCT, PMTCT and/or ART guidelines?
4. Could you please provide me with a copy of the written guidelines?
5. Has the Ministry of Health supported training of health workers and managers on the integration of Family planning services with HIV services?
6. Has the Ministry of Health or her partners provided financial support for the integration of Family planning services with HIV services?
7. Could you provide a list of the international and local agencies that are involved with integration of these services in Uganda?
8. In which districts has implementation of integration of these services occurred and which health facilities?
9. What does the financial support go towards: drugs/supplies, training? Please elaborate
10. Does the Ministry of Health supervise the implementation of the integration of Family planning services with HIV services?
11. Is the policy development and implementation of integrated services informed by any research?
12. Has there been any evaluation of these programs?
13. Do the Ministry of Health and her partners involve the local community in policy development and implementation? Please elaborate

APPENDIX 12: Information sheet for Quantitative interview participants (English)

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

Information sheet for Quantitative interview participants

English version

My name is Barbara Nattabi. I am a PhD student at Curtin University in Perth, Western Australia. I am asking for your help in my project which is to understand the desire to have children among PLWHA and their access to family planning services. Some of the questions are very personal and you do not have to answer the ones you do not want to. You can stop taking part in the interview at any time and you can withdraw from this study at anytime including after this interview but before the project reports are completed. Your help with this project is completely voluntary. It is important for you to know that if you decide NOT to take part in this project, the health care and services provided by the Hospital will not be affected in any way. You will continue to receive the same care and services that you have been getting. There will NOT be any money paid to you for helping me.

The interview may take 1 hour. The nurse will record all your answers in a questionnaire. Your answers will be kept very safe in a locked cupboard, and I will be the only person who has a key to the cupboard. I will enter your answers into my computer but your name will not be entered. No-one will be able to match your name to the answers. If you are willing to help me with the interview, I will ask you to sign the consent form or make your mark.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 110/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning +61 8 9266 2784 or by emailing hrec@curtin.edu.au.

This research has also been approved by the Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology. I also have permission from the Hospital administrators to interview you. You can also contact the Medical Superintendent of the Hospital or the Doctor in charge of the AIDS clinic if you have any further questions or concerns about this study.

My personal contact details are:
Dr Barbara Nattabi
Centre for International Health
Curtin University of Technology
P O Box U1987
PERTH, WESTERN AUSTRALIA 6845
Phone: +61 8 92663226
Email: *barbara.nattabi@postgrad.curtin.edu.au*

My supervisors' details are:
Dr Jaya Earnest
Centre for International Health
Curtin University of Technology
P O Box U1987
PERTH, WESTERN AUSTRALIA 6845
Phone: +61 8 92664151
Email: j.earnest@curtin.edu.au

Thank you very much for your time

Dr Barbara Nattabi

APPENDIX 13: Information sheet for Quantitative interview participants (Luo)

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

Information sheet for Quantitative interview participants

Luo version

An nyinga Barbara Nattabi. An atye latin kwan me digiri mamalo loyo weng i Univaciti me Curtin matye i Perth, tung kupoto ceng me lobo Australia. Atye ka penyo kony ki boti i purujek ma atye ka yenyo ngec ma lube ki miti me nongo lutino ki lodo nyo codo kin nywal ikin joma tye ka kwo ki two jonyo. Lapeny mukene obigudu tam ma i cwinyi, itwero yero pe me gamogi ka onyo itamo ni lagam meno bicwero cwinyi. Itwero yero me giko gamo lapeny mo keken onyo weng i cawa mo keken kadi wa inge peny man ento ma peya repot me purujeki otum. Kony ma megi i purujek man tye weng i mitini. Myero inge ni kwero mino kony i purujek ni pe obibalo nongo yot kom ki i ot yat boti.ibi mede ki gamo kony ki tic mogo madong ono ibedo ka nongone. Cul mo keken obibedo pe pi kony an.

Peny man twero tero cawa acel. Dakta obi coyo ping lagam ducu ki boti I karatac me lapeny. Karatac man ki lagam ma ibimiyo bota kibigwoko I kabat ma dano mukene pe bi oo onyo yabo, an kena ma abi nenone. Abi ketolagami i komputa na ento nyingi pe obidonyo iye. Ngat mo pe bitwero kubu nyingi ki lagam ducu ma ibimiyo. Ka ibiye me konyo an ki peny man, abilego in me keto cingi I karatac me niyee.

Yenyo ngec man kiyee ni otime ki bot komiti ma neno lok I kom yenyo ngec me Curtin Univaciti (kimiyo ite namba HR 110/2008). Lumemba me komiti man ocoko lutedero, lupwonye madongo, lugwok cik, daktari ki lutela dini. Tic madit mamegi aye me gwoko twero pa dano ma bibedo I kwedo ngec man. Ka ibimito lubu ada pa lok man onyo itye ki gung cwiny onyo lapeny mukene coo waraga bot Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 nyo go cim I namba +61 8 9266 2784 (hrec@curtin.edu.au.).

Yenyo ngec man bene kiyee ni otime ki bot komiti ma neno lok I kom yenyo ngec me gang kwan me Public Health (yot kom pa lwak) I Makerere univaciti kacel ki kancil madi loyo I Uganda malude ki Science ki technology. Luloc me ot yat man bene oyee ni apeny in. itwero penyo dakta madit me ot yat man onyo dakta maloyo ot yat pi two jonyo ka itye ki lapeny mukene nyo lworo malude ki kwedo ngec man.

Lok ma lube ki an gin aye:
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Email: *barbara.nattabi@postgrad.curtin.edu.au*

Lok ma lube kin gat ma neno tic mera:
Dakta Jaya Earnest
Centre for International Health
Curtin University of Technology
P O Box U1987
PERTH, WESTERN AUSTRALIA 6845
Cim: +61 8 92664151
Email: j.earnest@curtin.edu.au

Apwoyo wunu me miya kare wu

Dakta Barbara Nattabi

APPENDIX 14: Information sheet for Qualitative interview participants (English)

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

Information sheet for Qualitative interview participants

English version

My name is Barbara Nattabi. I am a PhD student at Curtin University in Perth, Western Australia. I am asking for your help in my project which is to understand the desire to have children among PLWHA and their access to family planning services. In this interview, I will ask detailed questions about your desires and intentions to have children. Some of the questions are very personal and you do not have to answer the ones you do not want to. You can stop taking part in the interview at any time and you can withdraw from this study at anytime including after this interview but before the project reports are completed. Your help with this project is completely voluntary. It is important for you to know that if you decide NOT to take part in this project, the health care and services provided by the Hospital will not be affected in any way. You will continue to receive the same care and services that you have been getting. There will NOT be any money paid to you for helping me.

The interview may take 2 hours. So I can be accurate, I wish to record your answers on a tape recorder. Your answers will be kept very safe in a locked cupboard, and I will be the only person who has a key to the cupboard. I will enter your answers into my computer but your name will not be entered. No-one will be able to match your name to the answers. If you are willing to help me with the interview, I will ask you to sign the consent form, or make your mark.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 110/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning +61 8 9266 2784 or by emailing hrec@curtin.edu.au.

This research has also been approved by the Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology. I also have permission from the Hospital administrators to interview you. You can also contact the Medical Superintendent of the Hospital or the Doctor in charge of the AIDS clinic if you have any further questions or concerns about this study.

My personal contact details are:
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My supervisors' details are:
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Phone: +61 8 92664151
Email: j.earnest@curtin.edu.au

Thank you very much for your time

Dr Barbara Nattabi

APPENDIX 15: Information sheet for Qualitative interview participants (Luo)

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

Information sheet for Qualitative interview participants

Luo version

An nyinga Barbara Nattabi. An atye latin kwan me digiri mamalo loyo weng i Univaciti me Curtin matye i Perth, tung kupoto ceng me lobo Australia. Atye ka penyo kony ki boti i purujek ma atye ka yenyo ngec ma lube ki miti me nongo lutino ki lodo nyo codo kin nywal ikin joma tye ka kwo ki two jonyo. Lapeny mukene obigudu tam ma i cwinyi, itwero yero pe me gamogi ka onyo itamo ni lagam meno bicwero cwinyi. Itwero yero me giko gamo lapeny mo keken onyo weng i cawa mo keken kadi wa inge peny man ento ma peya repot me purujeki otum. Kony ma megi i purujek man tye weng i mitini. Myero inge ni kwero mino kony i purujek ni pe obibalo nongo yot kom ki i ot yat boti.ibi mede ki gamo kony ki tic mogo madong ono ibedo ka nongone. Cul mo keken obibedo pe pi konywa.

Peny man twero cwalo cawa aryo. Wek pe akeny gim mo keken, abi mako lagam megi weng I recorder. Lagam ma ibimiyo bota kibigwoko I kabat ma dano mukene pe bi oo onyo yabo, an kena ma abi nenone. Abi ketolagami i komputa na ento nyingi pe obidonyo iye. Ngat mo pe bitwero kubu nyingi ki lagam ducu ma ibimiyo. Ka ibiye me konyo an ki peny man, abilego in me keto cingi I karatac me niyee.

Yenyo ngec man kiyee ni otime ki bot komiti ma neno lok I kom yenyo ngec me Curtin univaciti (kimiyo ite namba HR 110/2008). Lumemba me komiti man ocoko lutedero, lupwonye madongo, lugwok cik, daktari ki lutela dini. Tic madit mamegi aye me gwoko twero pa dano ma bibedo I kwedo ngec man. Ka ibimito lubu ada pa lok man onyo itye ki gung cwiny onyo lapeny mukene coo waraga bot Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 nyo go cim I namba +61 8 9266 2784 (hrec@curtin.edu.au.).

Yenyo ngec man bene kiyee ni otime ki bot komiti ma neno lok I kom yenyo ngec me gang kwan me Public Health (yot kom pa lwak) I Makerere univaciti kacel ki kancil madi loyo I Uganda malude ki Science ki technology. Luloc me ot yat man bene oyee ni apeny in. itwero penyo dakta madit me ot yat man onyo dakta maloyo ot yat pi two jonyo ka itye ki lapeny mukene nyo lworo malude ki kwedo ngec man.

Lok ma lube ki an gin aye:
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Email: j.earnest@curtin.edu.au

Apwoyo matek I me miyo cawani

Dakta Barbara Nattabi

APPENDIX 16: Information sheet for Health facilities in Northern Uganda

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

Information sheet for Health facilities in Northern Uganda

Dear Sir/Madam,

My name is Dr. Barbara Nattabi. I am a PhD student at Curtin University in Perth, Western Australia. I am also a medical doctor and public health specialist from Uganda.

I am asking for your assistance in my project which is to understand the factors that influence fertility desires of people infected with HIV. In this interview, I am asking questions on the integration of family planning services with HIV programs in your facility and other relevant services and indicators. I will be also interviewing PLWHA on their fertility desires and intentions to have children and access to family planning services in the region.

I have prepared the healthy facility tool for study purposes only. For your own personal confidence, I would like to confirm that all the data and information provided herein:

- are requested exclusively for study purposes
- are anonymous
- will remain strictly confidential
- will be collected and analysed exclusively by myself
- are intended to produce results which will be used with the aim of improving the quality and comprehensiveness of the services provided to patients

It may take you about 2 hours to fill in the tool. Your answers will be kept very safe in a locked cupboard, and I will be the only person who has a key to the cupboard. I will enter your answers into my computer but your name will not be entered. No-one will be able to match your name to the answers. You can stop taking part in the interview at any time and you can withdraw from this study at anytime including after this interview but before the project reports are completed

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 110/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning +61 8 9266 2784 or by emailing hrec@curtin.edu.au.

This research has also been approved by the Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology.

My personal contact details are:
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Thank you very much for your time

Dr Barbara Nattabi

APPENDIX 17: Information sheet for Ministry of Health Uganda

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

Information sheet for Ministry of Health Uganda

Dear Sir/Madam,

My name is Dr. Barbara Nattabi. I am a PhD student at Curtin University in Perth, Western Australia. I am also a medical doctor and public health specialist from Uganda.

I am asking for your assistance in my project which is to understand the factors that influence fertility desires of people infected with HIV. In this interview, I am asking detailed questions about the policies and supervision role of the Ministry of Health as regards the integration of family planning services with HIV programs in Uganda in general and specifically in Northern Uganda. I will be also interviewing health workers in Northern Uganda on integration of these services at health facility level as well as PLWHA on their fertility desires and intentions to have children and access to family planning services.

I have prepared the question guide for study purposes only. For your own personal confidence, I would like to confirm that all the data and information provided herein:

- are requested exclusively for study purposes
- are anonymous
- will remain strictly confidential
- will be collected and analysed exclusively by myself
- are intended to produce results which will be used with the aim of improving the quality and comprehensiveness of the services provided to patients

The interview may take about 1 hour. So I can be accurate, I wish to record your answers on a tape recorder. Your answers will be kept very safe in a locked cupboard, and I will be the only person who has a key to the cupboard. I will enter your answers into my computer but your name will not be entered. No-one will be able to match your name to the answers. You can stop taking part in the interview at any time and you can withdraw from this study at anytime including after this interview but before the project reports are completed.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 110/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning +61 8 9266 2784 or by emailing hrec@curtin.edu.au.

This research has also been approved by the Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology.

My personal contact details are:
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Thank you very much for your time

Dr Barbara Nattabi

APPENDIX 18: Information sheet for Ministry of Health partners in Uganda

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

Information sheet for Ministry of Health partners in Uganda

Dear Sir/Madam,

My name is Dr. Barbara Nattabi. I am a PhD student at Curtin University in Perth, Western Australia. I am also a medical doctor and public health specialist from Uganda.

I am asking for your assistance in my project which is to understand the factors that influence fertility desires of people infected with HIV. In this interview, I am asking detailed questions about your role in the formation of policies and implementation as regards the integration of family planning services with HIV programs in Uganda in general and specifically in Northern Uganda. I will be also interviewing health workers in Northern Uganda on integration of these services at health facility level as well as PLWHA on their fertility desires and intentions to have children and access to family planning services.

I have prepared the question guide for study purposes only. For your own personal confidence, I would like to confirm that all the data and information provided herein:

- are requested exclusively for study purposes
- are anonymous
- will remain strictly confidential
- will be collected and analysed exclusively by myself
- are intended to produce results which will be used with the aim of improving the quality and comprehensiveness of the services provided to patients

The interview may take about 1 hour. So I can be accurate, I wish to record your answers on a tape recorder. Your answers will be kept very safe in a locked cupboard, and I will be the only person who has a key to the cupboard. I will enter your answers into my computer but your name will not be entered. No-one will be able to match your name to the answers. You can stop taking part in the interview at any time and you can withdraw from this study at anytime including after this interview but before the project reports are completed

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 110/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning +61 8 9266 2784 or by emailing hrec@curtin.edu.au.

This research has also been approved by the Makerere University School of Public Health Institutional Review Board and the Uganda National Council for Science and Technology.

My personal contact details are:
Dr Barbara Nattabi
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Phone: +61 8 92664151
Email: j.earnest@curtin.edu.au

Thank you very much for you time.

Dr Barbara Nattabi

APPENDIX 19: Consent form for interview participants (English)

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

CONSENT FORM FOR INTERVIEW PARTICIPANTS

ENGLISH VERSION

Date: _____

My name is _____

My address is _____

The interpreter has read the information sheet about this project to me and I am willing to be interviewed. I am helping voluntarily and I understand that I will not be paid or given any sort of gifts for my help.

I understand that I can withdraw from this study at any time including after this interview has been completed but before the project reports are completed. I am helping with the project on the understanding that my answers will be kept confidential, and my name will not be associated with my answers.

I agree to the interview being taped. ☐

I prefer that the interview is not taped. ☐

I understand that my answers will be added together with responses from other people and that this information will be used in reports and publications. I agree to this on the understanding that my name or any other information that identifies me is not used.

All my questions about this project have been adequately answered.

Signed …….

Print Name……

Date……/……/……

Witness……..Print Name……

Please hand this sheet back

APPENDIX 20: Consent form for interview participants (Luo)

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

CONSENT FORM FOR INTERVIEW PARTICIPANTS

LUO VERSION

Nino dwe: _____

Nyinga _____

Kabedo na _____

Lagony ter lok otyeko kwano waraga ngec malube ki purujek bota ki an atye adyere me yee ni ki penya. Atye ka mino kony labongo cul mo,dok aniang ni pe ki bi cula onyo kibimina mic mo macalo adwogi me peny man.

Aniang ni atwero weko peny man icawa mo keken kadi bedi inge tum pa peny ento mapiya coyo ripot me purujeki otum. Atye ka konyo ki purujeki iniang ni legam ma abimiyo kibiwoko i mung, nyinga pe obibedo ka mo keken ikom lagam ma amiyo.

Aye ni lapenya obitiyo ki lamak dwon. ☐

Amito ni lapenya pe omak dwona ☐

Aniang ni lagam mamega obibedo lamed kacel ki lagam ki bot jo mukene ki ngec kibi tic kede i repot me miino ngec. Aye me niang ni nyinga onyo ngec mukene ma nyuta woko pe kitiyo kede.

Lapenya ducu ma atye kwede ma lubu purujek man ogamme ducu maber.

Keto cing …….

Cono nying……

Nino dwe……/……/……

Caden……..Cono nying……

Tim ber idwok karataci cen

APPENDIX 21: Consent form for Health facility administrators

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

CONSENT FORM FOR HEALTH FACILITY ADMINISTRATORS

Date: _____

My name is _____

My address is _____

I have read the information sheet about this project and I am willing to fill in the health facility tool provided. I am helping voluntarily and I understand that I will not be paid or given any sort of gifts for my help.

I understand that I can withdraw from this study at any time including after this interview has been completed but before the project reports are completed. I am helping with the project on the understanding that my answers will be kept confidential, and my name will not be associated with my answers.

I am happy for the researcher to use my responses combined with those of others in reports and publications as long as my confidentiality is protected.

All my questions about this project have been adequately answered.

Signed …….

Print Name……

Date……/……/……

Witness……..Print Name……

Please hand this sheet back

APPENDIX 22: Consent form for Ministry of Health Officials

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

CONSENT FORM FOR MINISTRY OF HEALTH OFFICIALS

Date: _____

My name is _____

My address is _____

I have read the information sheet about this project and I am willing to be interviewed. I am helping voluntarily and I understand that I will not be paid or given any sort of gifts for my help.

I understand that I can withdraw from this study at any time including after this interview has been completed but before the project reports are completed. I am helping with the project on the understanding that my answers will be kept confidential, and my name will not be associated with my answers.

I am happy for the researcher to use my responses combined with those of others in reports and publications as long as my confidentiality is protected.

All my questions about this project have been adequately answered.

Signed …….

Print Name……

Date……/……/……

Witness……..Print Name……

Please hand this sheet back

APPENDIX 23: Consent form for Non-government organisation officials

RESEARCH PROJECT: Factors affecting fertility desires and intentions of HIV Positive Men and Women in Post-conflict Northern Uganda: a mixed methods study

CONSENT FORM FOR NON GOVERNMENT ORGANISATION OFFICIALS

Date: _____

My name is _____

My address is _____

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I understand that I can withdraw from this study at any time including after this interview has been completed but before the project reports are completed. I am helping with the project on the understanding that my answers will be kept confidential, and my name will not be associated with my answers.

I am happy for the researcher to use my responses combined with those of others in reports and publications as long as my confidentiality is protected.

All my questions about this project have been adequately answered.

Signed …….

Print Name……

Date……/……/……

Witness……..Print Name……

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APPENDIX 24: Characteristics of the 26 participants in the qualitative arm of study

Participant*	Age	Sex	Marital status	Education	Religion	Desire children	On HAART	Profession	State of children	Comments
C1	34	Female	Cohabiting	P.3	Catholic	No	Unknown	Housewife	1 alive	Known status for 7 years; not given birth since diagnosis
I1	37	Male	Married	Unknown	Catholic	Yes	Yes	Businessman	7 alive	Known status for 10 years, on HAART for 4.5 years; 2 children since diagnosis to two wives, both on HAART
N1	Unknown	Male	Married	S.1	Catholic	Yes	Yes	Unknown	3 alive	Known status for 5 years; wife also on HAART
C2	30	Female	Married	P.5	Catholic	No	Unknown	Unknown	2 alive 1 dead	Known status for 7 years; one child

Participant*	Age	Sex	Marital status	Education	Religion	Desire children	On HAART	Profession	State of children	Comments
										born after diagnosis; 4 month baby
I2	32	Male	Married	Vocational	Catholic	Yes	Yes	Farmer	3 alive	Known HIV status for 8 years
N2	Unknown	Female	Single	P.6	Catholic	No	Yes	Unknown	1 alive 2 dead	Known status for 2 years; no spouse
C3	20	Female	Single	S.1	Catholic	No	Unknown	Other	No children	Known HIV status for 10 years
I3	40	Male	Married	S.4	Catholic	Yes	Yes	Carpenter	3 alive, all HIV negative	Known status for 10 years; had one child after diagnosis; 3 brother died of AIDS, 9 orphans to look after
N3	34	Male	Married	P.7	Catholic	Yes	Yes	Unknown	3 alive 1 dead	Known status for 6 years; fathered 2

Participant*	Age	Sex	Marital status	Education	Religion	Desire children	On HAART	Profession	State of children	Comments
										children after diagnosis; first wife died of AIDS
C4	36	Female	Widow	P.6	Protestant	No	Yes	Unknown	5 alive; 2 of them HIV-infected	Known status for 9 years
I4	37	Female	Married	Teacher training	Catholic	No	No	Teacher	5 alive	Had one child after diagnosis, HIV status of this child unknown
N4	35	Female	Married	None	Catholic	No	Yes	Unknown	3 alive 2 dead	Known status for 4 years; 1st husband died; with new partner; no children after diagnosis
C5	38	Female	Married	P.7	Catholic	No	Yes	Unknown	4 alive 1 dead	Known status for 9 years

Participant*	Age	Sex	Marital status	Education	Religion	Desire children	On HAART	Profession	State of children	Comments
I5	30	Male	Married	P.7	Catholic	Not yet	Yes	Businessman	2 alive	Known status for 5 years; on HAART for 3 years; no child since diagnosis
N5	Unknown	Male	Married	None	Catholic	No	No	Farmer	4 alive	One child after diagnosis
C6	40	Female	Married	P.7	Catholic	No	Yes	Unknown	4 alive	
I6	32	Male	Married	S.3	Protestant	No	Yes	Businessman	3 alive	Known status for 6 years
N6	Unknown	Female	Married	S.4	Catholic	No	Unknown	Unknown	3 alive	Known status for 3 years; no child since diagnosis
C7	35	Female	Married	S.3	Protestant	No	Yes	Unknown	2 alive	Known status for 5 years; one child since diagnosis
I7	40	Male	Married	S.3	Protestant	Yes	Yes	Other	6 alive	Known status for 6 years; been on

Participant*	Age	Sex	Marital status	Education	Religion	Desire children	On HAART	Profession	State of children	Comments
										HAART for 5 years; all children negative; wife HIV negative
C8	42	Female	Widow	None	Protestant	No	Unknown	Unknown	6 alive	Known status for 5 years
I8	32	Male	Married	Vocational	Catholic	Yes	Yes	Unknown	6 alive	Known status for 3 years; fathered 2 children after diagnosis
C9	40	Female	Unknown	P.6	Catholic	No	Unknown	Unknown	6 alive	Known diagnosis for 8 years; no children after diagnosis
I9	34	Male	Separated	P.7	Protestant	Yes	Yes	Farmer	2 alive	Known status for 9 years; no children after diagnosis
C10	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	Unknown	

Participant*	Age	Sex	Marital status	Education	Religion	Desire children	On HAART	Profession	State of children	Comments
I10	35	Male	Married	S.1	Catholic	Yes	Unknown	Unknown	3 alive, all HIV negative	Known status for 20 years; no children since diagnosis

* To preserve confidentiality, I have identified the 26 participants by a number and an initial from the interviewer's names; HAART, highly active antiretroviral therapy

APPENDIX 25: Co-authors signatures

TO WHOM IT MAY CONCERN

The conceptual development, design and writing of the following papers listed below were led by Barbara Nattabi. All co-authors have contributed to the design of the study and interpretation of the results, commented on and edited multiple drafts of the papers, and approved the final versions of journal articles for submission to peer-reviewed journals.

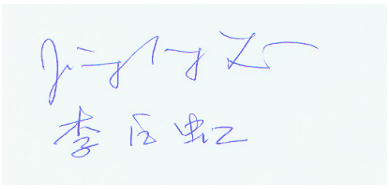
1. Nattabi, Barbara., Li, Jianghong., Thompson, Sandra. C., Orach, Christopher. Garimoi., & Earnest, Jaya. (2009). A systematic review of factors influencing fertility desires and intentions among people living with HIV/AIDS: Implications for policy and service delivery. *AIDS and Behavior, 13*(5), 949-968. doi: 10.1007/s10461-009-9537-y

2. Nattabi, Barbara., Li, Jianghong., Thompson, Sandra. C., Orach, Christopher. G., & Earnest, Jaya. (2011). Factors associated with perceived stigma among people living with HIV/AIDS in post-conflict Northern Uganda. *AIDS Education and Prevention, 23*(3), 193-205. doi: 10.1521/aeap.2011.23.3.193

3. Nattabi, Barbara., Li, Jianghong., Thompson, Sandra. C., Orach, Christopher. G., & Earnest, Jaya. (2011). Family planning among people living with HIV in post-conflict Northern Uganda: a mixed methods study. *Conflict and Health, 5*(18). doi: 10.1186/1752-1505-5-18

4. Nattabi, Barbara., Li, Jianghong., Thompson, Sandra. C., Orach, Christopher. G., & Earnest, Jaya. (under review). Between a rock and a hard place: Stigma and the desire to have children among people living with HIV in Northern Uganda.

Barbara Nattabi
(Candidate and 1st author)



(Signature of Co-Author)
Dr Jianghong Li

(Signature of Co-Author)
Associate Professor Jaya Earnest

(Signature of Co-Author)
Dr Chris Garimoi Orach

(Signature of Co-Author)
Winthrop Professor Sandra C Thompson

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